

**‘Place Bonding’:
Parents’ Journeys
Towards a Sense of Rootedness
in Children’s Hospice Care**

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Abstract

The number of children with life-limiting and life-threatening conditions in the UK is rising. In response to the reality that many children are living longer and complexities of care are increasing, providers of palliative care services are tasked with developing flexible approaches to delivery of care. Children's hospices are key players in this. However, evidence suggests that only a small percentage of parents of children with life-limiting and life-threatening conditions choose to access hospice services. This study explored parents' perspectives of existing hospice and palliative care services in one region of England. Barriers and facilitators to accessing services, the types and characteristics of hospice services parents wanted and how best these services could be delivered to meet the needs of the population of children with life-limiting and life-threatening conditions were considered.

A two phase qualitative study underpinned by a constructivist grounded theory methodology was employed for the study. In Phase 1 focus groups were used to collect data from twenty four parents of children accessing services at the hospice. In Phase 2 in-depth semi-structured interviews were conducted with seven parents of children who did not use services at the hospice and with a further seven parents who had either previous experience of the hospice or were using a hospice outside of the region. Data derived from the interviews were analysed using a grounded theory method. Three main themes were generated: Coming 'Home'; This is Living Now; and Moving Forward. A theory of place bonding was developed which reflects how affective bonds develop over time between parents of children with life-limiting conditions and the hospice. The five dimensions of place bonding: place familiarity, place identity, place belongingness and place association led to a deeper sense of place rootedness and established bonds with the hospice. Finding a place where they belonged and where they felt at 'home' made the decision to accept help in caring for their child with a life-limiting condition more manageable. The thesis concludes by acknowledging the importance of place bonding and its potential to influence practice for children's hospices and also in providing a platform for service development for other respite situations for children and young people with life-limiting conditions.

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Glossary of Terms

Children's palliative care: An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (Baum et al., 1997).

End of life: The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health/social care professional or team responsible for the care of the patient, but it is often the child/young person or family who first recognises its beginning.

End of Life Care: End of life care is care that helps all those with advanced, progressive, incurable illness, to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and the family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement.

Life-limiting conditions/life-shortening conditions: Life-limiting/life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

Life-threatening conditions: Life-threatening conditions are those for which curative treatment may be feasible but can fail. Children in long-term remission or following successful curative treatment are not included.

Child: A child is defined as a young person aged up to their 19th birthday.

Young person: A generic term used in this study to describe teenagers and young adults up to the age of twenty five years.

Respite/respite care (short breaks): the provision by appropriately trained individuals of care for children with life-limiting conditions for a specific period of time thus providing temporary relief to the usual care giver. Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person. ¹

¹ Definitions taken from Together for Short Lives: Children's Palliative Care Definitions

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Chapter 1 Introduction

This chapter gives a brief background to the development of paediatric palliative care and children's hospice care in the UK. In setting the scene for the study the chapter will consider some of the current challenges and recent developments in paediatric palliative care. The setting in which the study takes place is described in terms of its history and the challenges it faces in meeting the changing needs of children, young people and their parents. The origins of the study are outlined by contextualising the questions raised by the Board of Trustees at the hospice. The chapter concludes with an outline of the structure of the thesis.

1.1 Overview of the Growth of Paediatric Palliative Care and Children's Hospices in the UK

The hospice movement began in the UK in 1967 with the opening, by Dame Cicely Saunders, of the first adult hospice, St Christopher's Hospice, in London. The focus of the hospice was to provide a dignified and comfortable death for adults dying of incurable diseases. Dame Saunders' vision of palliative care to meet the physical, psychosocial, emotional and spiritual needs of the patient at the end of life subsequently became embedded within the hospice philosophy (Saunders, 2001). The growth of palliative care in children emerged more slowly than adult palliative care. It took until 1997 for paediatric palliative care (PPC) to be recognised and, in a joint document published by the Royal College of Paediatrics and Child Health (RCPCH) and the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), paediatric palliative care was defined as an:

“active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement” (Baum et al, 1997:7).

The allocation of seventy million pounds from the New Opportunities Fund in 2001 (now known as the Big Lottery Fund via the National Lottery) enabled many local initiatives to be developed throughout England to support and improve adult and children's palliative

care services (Big Lottery Fund, 2006). Specialist community nursing teams and hospice services were founded in commemoration of the life of Diana, Princess of Wales; many of these teams functioned under a title of palliative care nursing teams. However, following concerns that children's palliative care services had developed in a sporadic and unplanned way via short term and often charitable funding streams (Craft and Killen, 2007), the first national strategy for children's palliative care was published (DH, 2008). The report called for accurate assessment of population needs, joint commissioning of services, empowerment of families and the provision of high quality family centred care provided in a setting of their choice. Subsequently further monies were made available by the Department of Health to fund further projects and resources in paediatric palliative care (see www.30millionstars.org.uk).

However, in 2010 in response to continued concerns regarding the sustainability of palliative care services, a review of palliative care funding in England was commissioned by the Secretary of State for Health. The subsequent report recommended that, in order to create a fairer and more transparent funding mechanism, the collection of robust data and a per-patient NHS tariff to meet the needs of the patient regardless of care provider, should be trialled (Hughes-Hallett et al, 2011). The purported 'palliative care currency' is in development, in which specialist palliative care packages of care are grouped and costed in terms of resource need and clinical input (NHS England, 2015). Furthermore a clinical practice guideline to define quality standards for children's end of life care by the National Institute for Health and Care Excellence (NICE) is under consultation (www.nice.org.uk). In the UK the Association for Children's Palliative Care (ACT) and Children's Hospices UK (CHUK) have continued to champion the development of palliative care in children. Following the merger of these two organisations in October 2011, the newly formed Together for Short Lives became the national charity in the UK for children with life-limiting and life-threatening conditions. They have been instrumental in developing standards of care, outlining key pathways for children's palliative care and supporting research in the UK.

As the speciality of paediatric palliative care has developed so has the recognition that there were many children with life-limiting conditions representing an extremely wide range of diagnoses (in excess of 300 diagnoses) (Hain et al, 2013). There is also an overlap of diagnostic groups with those children with severe disabilities and complex needs (Craft

and Killen, 2007; Fraser et al, 2011a; Hain et al, 2013). Subsequently the terms 'life-limiting' and 'life-threatening' have come to be used to describe children who need or will in the future need access to palliative care services (Cooley et al, 2000; Davies, 2003; Cochrane et al., 2007; Doug et al, 2011; Hain et al., 2012; Himmelstein, 2006; ACT, 2009). For the purposes of this study, the term 'life-limiting' is used to describe children diagnosed with a condition for which there is no reasonable hope for curative treatment and from which they will die in childhood or early adulthood. The term 'life-threatening' is applicable to children with conditions that may be curable but may also fail to respond to treatment (ACT, 2009).

As the field of children's palliative care has grown so has the notion that it is different from adult palliative care. In contrast to adult palliative care which focused historically on terminal care and end of life management, palliative care for children has been described as support offered to the child and family from the time of diagnosis throughout the whole disease trajectory (WHO, 2002; Liben et al. 2008; Himmelstein, 2006; McNamara-Goodger and Cooke, 2008). For many children with life-limiting or life-threatening conditions the trajectory of disease is not certain. A common pattern described in the literature amongst children who may require palliative care services, are periods of stability interjected with periods of crisis (Cochrane et al., 2007; Doug et al, 2011; Hain et al., 2012). Prevalence data in England alone over a ten year period (2000-2010) showed that the numbers of children requiring palliative care services had been seriously underestimated (Fraser et al, 2011b, 2013). Moreover, due to advances in medical and nursing care, more children with complex healthcare needs live longer and subsequently require palliative care services for longer periods of time (Fraser et al, 2011b, Noyes et al, 2013). Some children even need access to services and support over decades and into adulthood (Doug et al, 2011; Fraser et al, 2012a, 2013).

As the care of many children with palliative care needs is managed primarily at home by their parents, the result is that the greatest need for families has been the provision of short periods of respite care for their child. In 1982, Helen House in Oxford, the first children's hospice was opened not as a place of dying, but as a 'home from home', an environment to offer practical help and respite to families (Dominica, 1982). At the time of writing this thesis in mid-2016 there were fifty three hospices for children throughout the UK (TfSL, n.d. (a)) aimed at meeting the physical, emotional, spiritual and social needs

of both child and family. In addition to providing short breaks, children's hospices provide stepped discharge from hospital, support for the whole family, access to emergency care, practical help and advice, specialist therapy services including physiotherapy, music and play therapy, information and training to carers, symptom management, 24 hour end of life care and bereavement support.

Relative to the numbers of children with life-limiting and life-threatening conditions the overall numbers accessing hospice services is low (Devanney and Bradley, 2012). The fact that paediatric palliative care has grown out of the adult hospice movement may have affected public perception of children's hospices and the services they deliver. However, there is evidence that children's hospices are now supporting more young people over the age of 16 years (Devanney and Bradley, 2012), one third of children's hospices in the UK have a separate wing for the care and management of young people/adults ranging from 18 to 35 years (Devanney and Bradley, 2012). Whilst there is some evidence of the challenges of transitioning from children's to adult services for children with chronic illness and disability (Kirk, 2008; Beresford, 2004; Lotstein et al. 2005), service transition for children with life-limiting conditions has been less well researched. Unlike adult palliative care where many patients have malignant conditions most young people transitioning to adult services with life-limiting conditions have neuromuscular, neurodegenerative and metabolic diagnoses (Fraser et al. 2011a; 2012b).

In response to the expectation that children with life-limiting/threatening conditions live longer, flexible approaches to integrating palliative care into existing medical care and better preparation for transition into adult palliative care services are required. However, this growing population of young people with palliative care needs creates future challenges for adult services. Parents potentially will remain directly and indirectly involved in care. Different ranges and trajectories of disease and complexities of care may mean that adult physicians are insufficiently prepared to deliver effective care and there may be insufficient resources to provide adequate services to meet needs. Adult hospices are also considering their role in the care of these young people.

1.2 The Setting for the Study

Woodlands Hospice for Children and Young People (pseudonym) was opened as a charity, to provide palliative and end of life care and support for children with a life-limiting condition and their families, living in the local region. When Woodlands first opened it was a six-bedded children's hospice providing care for children who were not expected to live beyond the age of 19 years. In those days, Woodlands cared for very few teenagers and most children who used the hospice died before they reached teenage years. Today, the demography of the children and young people that access Woodlands has changed, and their needs are quite different. Woodlands now supports many children and young people with life-limiting and life-threatening conditions, including: children with degenerative conditions that will lead to death before or during early adulthood; children who are likely to die within two years and require palliative care and; premature babies and children who require life sustaining long term ventilation. In response to local need, recognising that children were surviving longer and potentially would need to transition to adult services, a new wing of the hospice was opened and services expanded to meet the needs of young adults from 18 years to 25 years of age. The hospice also recognised that some young adults receiving their services would live beyond 25 years and deemed it appropriate for those young people to continue to use the hospice until the age of 30 years.

Since the opening of the additional facilities Woodlands has seen many changes in the way in which care is accessed and delivered outside of the hospice. Many families now access a personal health budget and can commission their own care and increasing numbers of services are provided by non-NHS organisations. In response to these changes, Woodlands is having to consider different ways of sustaining and developing their services to meet the needs of their families locally. At the beginning of the study (October 2013) there were 258 children with life-limiting conditions accessing services from Woodlands, accounting for less than 10% of the estimated population of children aged 0-19 years with life-limiting conditions living in the region as identified by Fraser et al. (2011b). This raised many questions for the Board of Trustees at the hospice such as: why were children not accessing the hospice? whether their palliative care needs were being met elsewhere? and, what could the hospice do to further support families in the region? Following

detailed consideration, the hospice sponsored this study to address the following questions:

- What are parents' perspectives of existing and potential children's hospice and palliative care services within the region?
- What are the barriers and facilitators in accessing children's hospice and palliative care services for parents and children with life-threatening/life-limiting conditions across the region?
- What are the types and characteristics of children's hospice and palliative care services that parents of children with life-threatening/life-limiting conditions, living in the region want?
- How best can services be delivered to maximise impact on the family?

This thesis presents the study undertaken to generate insights and answers to the questions highlighted above.

1.3 Outline of the Thesis

In addition to this introductory chapter the thesis is set out in chapters as follows:

Chapter 2: Literature review

This chapter presents a narrative review of the literature pertaining to paediatric palliative and hospice care and sets the scene for the subject area. The appropriateness of conducting and reviewing literature within a grounded theory methodology is explored. Following this the strategy for accessing the literature is discussed. Three key areas of literature are considered: the prevalence of children with palliative care needs; the challenges of paediatric palliative care for health professionals and parents; and the delivery of palliative care services.

Chapter 3: Methodology, Design and Conduct of the Study

This chapter describes the rationale for the choice of the qualitative approach that has been adopted for the study and constructivist grounded theory, the methodology underpinning the study. Following this a comprehensive account of the design and conduct of the two phases in the study is presented: the approach to gain approval for the study and the ethical challenges faced; the strategy for recruitment; and methods used for

data collection. The chapter concludes with a description of the process used for data analysis and how this was influenced by the methodology chosen.

Chapters 4, 5 and 6: Findings

These three chapters present the detailed findings formed from the grounded theory analysis of the focus groups conducted in phase 1 and the semi-structured interviews conducted in phase 2 of the study. In chapter 4, the findings associated with the theme 'Coming Home' are presented; in Chapter 5 the theme 'This is Living Now' is considered and finally in Chapter 6 the findings associated with the theme 'Moving Forward' are described.

Chapter 7: Discussion and Analysis

In this chapter the ideas underpinning Coming 'Home', This is Living Now and Moving Forward and their associated categories are explored in light of Hammitt et al.'s (2004, 2006) five dimensions of place bonding: place familiarity, place identity, place belongingness, place dependence and place rootedness. The theory developed – 'Place Bonding: Parent's journeys towards a sense of rootedness in children's hospice care' – provides an explanation and understanding of the conceptual journey that parents undergo as they grapple with their decision to seek help in the form of respite care which is hospice based. The chapter continues with a discussion of the contribution the theory makes to new knowledge in paediatric palliative and hospice care.

Chapter 8: Conclusions and Recommendations

In this chapter a summary of the key findings and their implications for clinical practice and education are presented. Strategies employed to ensure quality throughout the research process are introduced together with a discussion of the strengths and limitations of the study. Recommendations for practice and policy and the development of services in the region and beyond are made. Proposals for dissemination of the findings of the study together with suggestions for further research are highlighted.

Chapter 2 Review of the Literature

This chapter presents a review of the literature relevant to the area of paediatric palliative and hospice care. This chapter begins by considering the appropriateness of conducting and reviewing literature prior to data collection within a grounded theory methodology. Following this the strategy for accessing the literature is discussed. Finally, the available literature is presented as a narrative account which summarises and highlights important issues and trends within the current body of knowledge related to paediatric palliative care.

Narrative literature reviews are used when the focus is on bringing together, summarising and describing the body of evidence which deals with a given topic (Mays et al., 2005; Crowther and Cook, 2007), in this case paediatric palliative care. Traditionally, the methods used to review the literature are less explicit than those used in for example, a systematic review (Crowther and Cook, 2007). Drawing upon qualitative and/or quantitative evidence the review is often presented as a form of thematic analysis which identifies the main, recurrent issues arising from the literature (Mays et al., 2005). In this review three main themes are presented in a holistic account: the prevalence of children with palliative care needs, challenges of paediatric palliative care for professionals and parents and the variation in models of delivery of palliative care services for children.

2.1 Reviewing Literature in the Context of Grounded Theory Methodology

The issue of how and when literature relevant to the research topic should be used is not straightforward in Grounded Theory (Bryant and Charmaz, 2007). Arguments have been based on the fact that engaging with the literature prior to data collection has the propensity to direct data collection and influence analysis by imposing preconceived ideas on the data (Glaser, 1992; Strauss and Corbin, 1998). Whilst Charmaz acknowledges the reasoning for delaying a literature review, she also suggests that by ignoring the literature a researcher is a risk of “*rehashing old empirical problems*” (Charmaz, 2014:306). Instead there is a greater consensus that it is impossible for professionals to approach a research inquiry totally free from perspectives and knowledge of the literature in the field (Clarke, 2005; Lempert, 2007; Thornberg, 2012; Charmaz, 2014). Thornberg (2012) also highlights that in the current process of undertaking research and applying for grants, or

in the case of this study seeking sponsorship, researchers are expected to have a basic knowledge underpinning the proposals for their work.

Charmaz (2014:308) suggests that the researcher should use the literature review to “*set the stage*” to inform the development of the research inquiry and following this the material highlighted by the literature review should be left until the data analysis is completed. At this point the researcher returns to the literature using it to clarify, compare, analyse and synthesise the theory developed in the current study. In doing so an initial awareness of the literature acts as a baseline to enable the researcher to engage in theoretical sensitivity and position their arguments and their contribution within the existing body of knowledge (Lempert, 2007). In this chapter, the initial literature review that occurred early in 2014 is presented. The literature reviewed following data analysis and its contribution to the developed grounded theory will be presented in chapter 7.

2.2 Strategies Employed to Review the Literature

The initial strategy for this study was to keep the search as broad as possible. Initially five key electronic databases were explored; British Nursing Index (BNI), Cumulative Index to Nursing and Allied Health Professionals (CINAHL), Medline (Pubmed), Academic Search Premier (EBSCO) and Scopus. Key internet sites were examined including Department of Health www.dh.gov.uk, Together for Short Lives www.togetherforshortlives.org and Help the Hospices www.helpthehospices.org.uk. Search engines, Google, Google Scholar and Science Direct were used to locate source articles. The primary terms used initially were paediatric palliative care, children’s hospice care and paediatric palliative care provision. The definition of ‘child’ was considered broadly, search terms and different spellings were considered. Table 2.1 shows the phrases and words that were then grouped together and entered in various combinations to each of the databases, using Boolean operators, AND or OR, to connect the combination of terms. This resulted in over 2600 possible articles.

Table 2.1 Words and phrases used to search databases

Paediatric Palliative Care Child, Children Paediatric, Pediatric Life-limiting conditions, illness Life-threatening conditions, illness Epidemiology of	Children’s Hospices Respite care Short breaks Barriers to Facilitators of Access to	Paediatric Palliative Care Provision PPC programmes, programs Barriers to Facilitators of Referral patterns Acceptability of Perspectives, Experiences, Needs of parents, health care professionals
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Filters available within the databases were used to refine results for example, the search strategy was linked to peer reviewed articles, available in full text, written in the English language published from when paediatric palliative care was first described by ACT in 1997 (Baum et al., 1997) until the present day 2014. Duplicate articles were also removed, resulting in just over 500 papers for further consideration. Titles of articles were screened for relevance, where the title indicated that the article may address objectives set for the study (see section 1.2), abstracts were then reviewed. Inclusion and exclusion criteria were then applied to the articles. Only articles from the global literature relating to palliative or hospice care amongst the paediatric population were included, titles that focused solely on adult palliative care were excluded. In some cases it was not explicit in the article if palliative care experience was related to adults, children or both and therefore if the article offered some insight to the objectives of the study it was retained. If articles focused on a specific disease area or treatment for example care of a child with a tumour it was excluded. Articles were considered relevant if they explicitly related to the wider experiences, use and acceptability of paediatric palliative care services or paediatric hospices.

After screening the abstracts, the resulting 61 articles were further scrutinised. Both the text and references were also examined for other potential papers that addressed the aims of the study. A key issue in reviewing articles is the appraisal of the quality of the qualitative and quantitative studies. Ingham-Broomfield's (2008) framework was used as a generic tool to appraise the methodological coherence of the 61 articles. Following this, 37 articles were retained for inclusion in the narrative review. Most articles reported original studies using primarily qualitative methodology although there were a small number of prospective cohort studies. Appendix 1 details an alphabetical summary of the methodological features, pertinent findings and limitations of the 37 articles. Hand searches of two key journals, Palliative Medicine and International Journal of Palliative Care and Together for Short Lives 'Synopsis' of children's palliative care research abstracts were also undertaken. An additional 20 papers were included; review articles in paediatric palliative care (n=11), government reports (n=5) and reports from charitable organisations (n=4). Whilst these papers met the search inclusion criteria they were of marginal methodological quality. However, in keeping with the nature of a narrative review to cover a wide range of literature and recognising that *"there are nuggets of wisdom in methodologically weak studies"* (Pawson, 2006:127) the decision not to exclude

these was made. However, I was critically aware of how much weight I would give such evidence in the narrative review. Alert mechanisms were also set up for the duration of the study to highlight and identify new studies in the field. Figure 2.1 is a flow diagram which summarises the steps taken in selecting the articles for inclusion within the narrative review.

Using a thematic analysis approach to the synthesis of the key issues identified from the narrative review of the literature (Mays et al., 2005) three key themes were produced and are presented in the account below:

- Prevalence of children with palliative care needs;
- Challenges of paediatric palliative care for health professionals and parents; and
- Delivery of palliative care services.

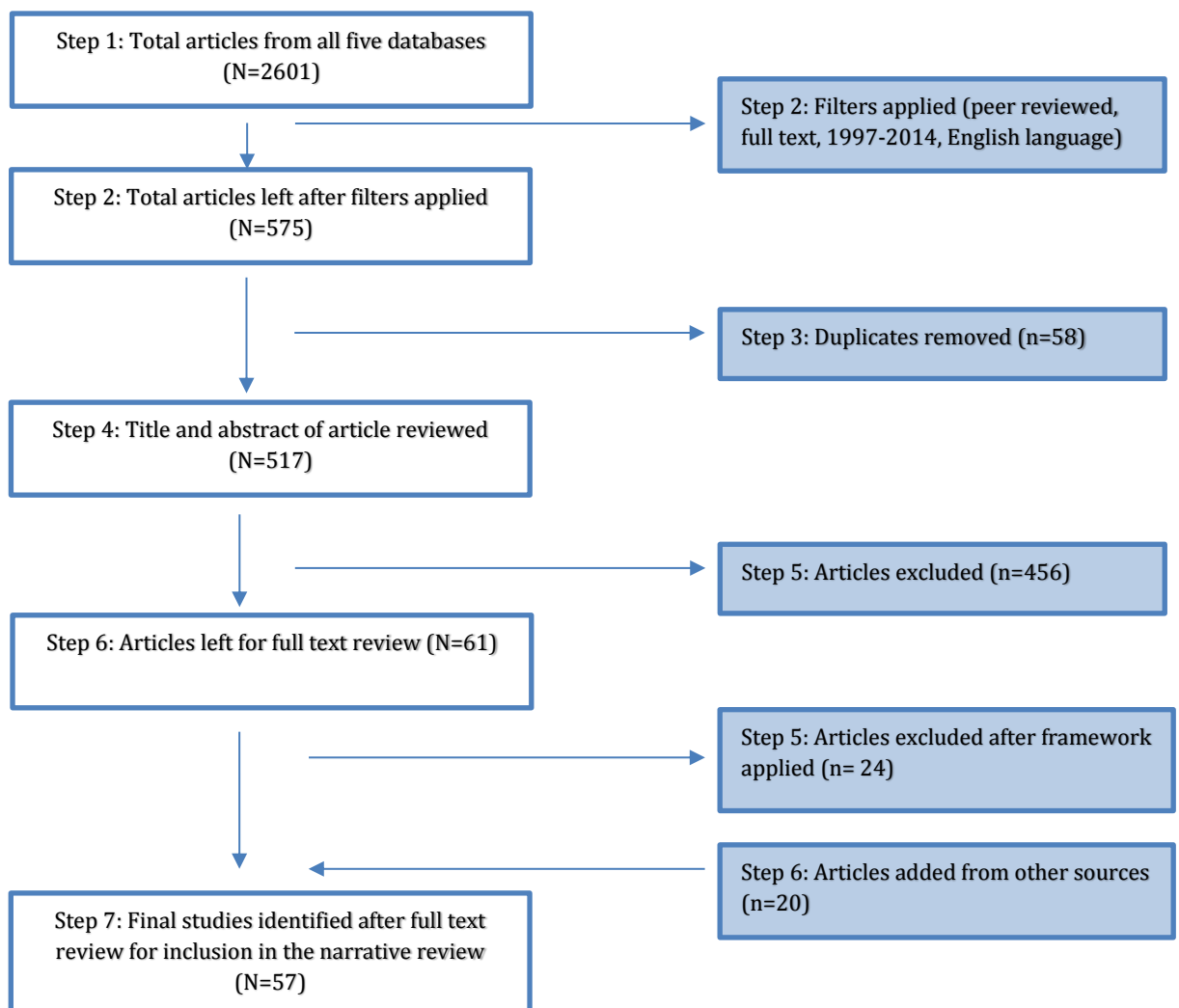


Figure 2.1 Flow diagram showing steps taken in selecting the articles for literature review

2.3 Prevalence of Children with Palliative Care Needs in the UK

Experts in paediatric palliative care have suggested that the introduction of palliative care services should be made much earlier in a child's disease trajectory (American Academy of Pediatrics, 2000; WHO, 2002). However, identifying those children in the UK most likely to benefit from such services has proved problematic for several reasons. In the UK because there is no national database of children with life-limiting conditions the number of children living with these conditions is unclear. Consequently there has been a growth in the number of studies which have focused on collecting precise and rigorous epidemiological data in the UK (Hain, 2005; Noyes et al., 2013, Fraser et al., 2011a, b; Fraser et al. 2013). Secondly the range of diverse and complex conditions in childhood has made it difficult to identify the numbers of children who would benefit from palliative care services. In response to this four typologies of life-limiting and life-threatening conditions in childhood have been described (Figure 2.1) (Baum et al., 1997). Categorisation is not easy and the examples of conditions given are not exclusive. However the four categories have raised awareness and offered some guidance globally of the types of diagnoses where children would benefit from a palliative care approach (Craft and Killen, 2007; EAPC Taskforce, 2007; Bradford et al., 2012).

Category 1 - Children with life-limiting conditions where cure is possible but can fail (e.g. cancer, heart failure).

Category 2 - Children with conditions which, though treated intensively over a period of time, inevitably lead to early death (e.g. cystic fibrosis (CF), human immunodeficiency virus (HIV), muscular dystrophy).

Category 3 - Children with progressive conditions where treatment is palliative and often over many years (e.g. Batten's Disease, Mucopolysaccharidosis).

Category 4 - Children with Irreversible but non-progressive conditions which give rise to severe disability, complex health needs and sometimes premature death (e.g. severe cerebral palsy, hypoxic brain injury).

Figure 2.2 Categories of life-limiting and life-threatening conditions in childhood (Baum et al., 1997).

2.3.1 Epidemiological studies

The first published prevalence in 1997 of children with life-limiting conditions in the UK was estimated as 10 per 10,000 children (Baum et al., 1997). However, as there was only limited data available at that time on conditions such as cancer, cystic fibrosis, Duchenne

muscular dystrophy and mucopolysaccharidosis it is unclear in the report (Baum et al. 1997) as to how this figure was reached. The report did highlight the urgent need for further robust data to be collected. Following this a study in Wales reported that in a two year period 2001-2002 there were 3.75 per 10,000 children requiring palliative care in Wales (Hain, 2005). This was a much lower figure than Baum et al. (1997) had predicted, the sense was that there was under-reporting amongst paediatricians because of the difficulty in identifying those children who needed palliative care.

The most recent epidemiological study in the UK of the prevalence of life-limiting and life-threatening conditions in children was conducted in England over a ten year period 2000 to 2010 of children aged 0 to 19 years (Fraser et al., 2011b). Using a combination of a list of life-limiting conditions compiled by Hain et al. (2013), the ICD-10 database of disease codes, and a list of diagnoses provided by a local hospice, children were identified from an analysis of routinely collected hospital inpatient data. From this over 1.7 million individual inpatient episodes were identified and the data were examined for diagnosis, geography and demographics. The highest prevalence of life-limiting conditions in the UK was amongst children with congenital anomalies (30.7%), followed by oncology (13.7%) neurology (12%), haematology (9.8%), respiratory (8.8%), genitourinary (6.2%), perinatal (7.7%), metabolic (3.8%), circulatory (3.8%), gastrointestinal (2.4%), and an "other" group (1.1%) (Fraser et al., 2012a). This was similar to the results of a multi-centre cohort study conducted in Canada and United States which found that the three most dominant conditions encountered in a paediatric palliative care setting were genetic/congenital (41%), followed by neuromuscular (39%) and then cancer (20%) (Feudtner et al., 2011).

The overall prevalence of children aged 0 to 19 years living in England with life-limiting conditions showed a rise from 25 per 10,000 population in 2000-2001 to 32 in 2009-2010 (Fraser et al., 2011b), with a total estimate of more than 40,000 children. Fraser's study (2011b) also highlighted that over the ten year period the prevalence of life-limiting conditions in the 16 to 18 year old age group had increased from 16.3 to 23.6 per 10,000 population. This suggested that the age of survival of children with life-limiting conditions was increasing. Whilst better reporting and gathering of data via hospital inpatient datasets could have contributed to the high prevalence rates it prompted further exploration of the population aged 18-40 years (Fraser et al., 2013). From this second

study, 12,827 young adults aged between 18 and 25 years living in England with life-limiting and life-threatening conditions were identified.

One of the limitations in the methodology for both studies (Fraser et al., 2011b, 2013) was that only hospital inpatient data were examined. Although data collected were over a period of ten years there was no way of knowing that all children with a life-limiting condition had been admitted to hospital during that time period, so some children's data may not have been captured. In a more recent study exploring the numbers of children in Scotland requiring palliative care (ChiSP Study), in addition to examining hospital inpatient episodes, data from community prescribing records were explored (Fraser et al., 2015). Knowing that most children with life-limiting conditions would have a prescription, it was anticipated that this would give a more accurate picture of prevalence rates and capture those children who had not had a hospital admission.

Despite concerns regarding the accuracy of the data collected in both studies (Fraser et al., 2011b, 2013) there is no doubt that the findings have begun to fill a gap in the knowledge base and provided information which can be cautiously extrapolated and used for service planning and development in palliative care.

2.3.1.1 The epidemiological data for the study setting

From an analysis of the demographic data gathered from both studies (Fraser et al. 2011b; 2013) children were allocated to the local authority district where they lived with the result that the prevalence rate of children with life-limiting conditions per region in England was identified. The section below identifies the prevalence data for the region in which this study took place. In the age range 0-19 years the overall number of children with life-limiting conditions living in the region rose from 2446 (in 2000 to 2001) to 3257 (in 2009 to 2010) representing a reported rise in prevalence rate per 10,000 population of children from 23.4 (in 2000-2001) to 30.4 (in 2009-2010)(Fraser et al., 2011a). Figure 2.2 shows the prevalence of life-limiting conditions in children by diagnostic group, living within the region where the study was conducted. Children with congenital anomalies were the most common group followed by neurological conditions.

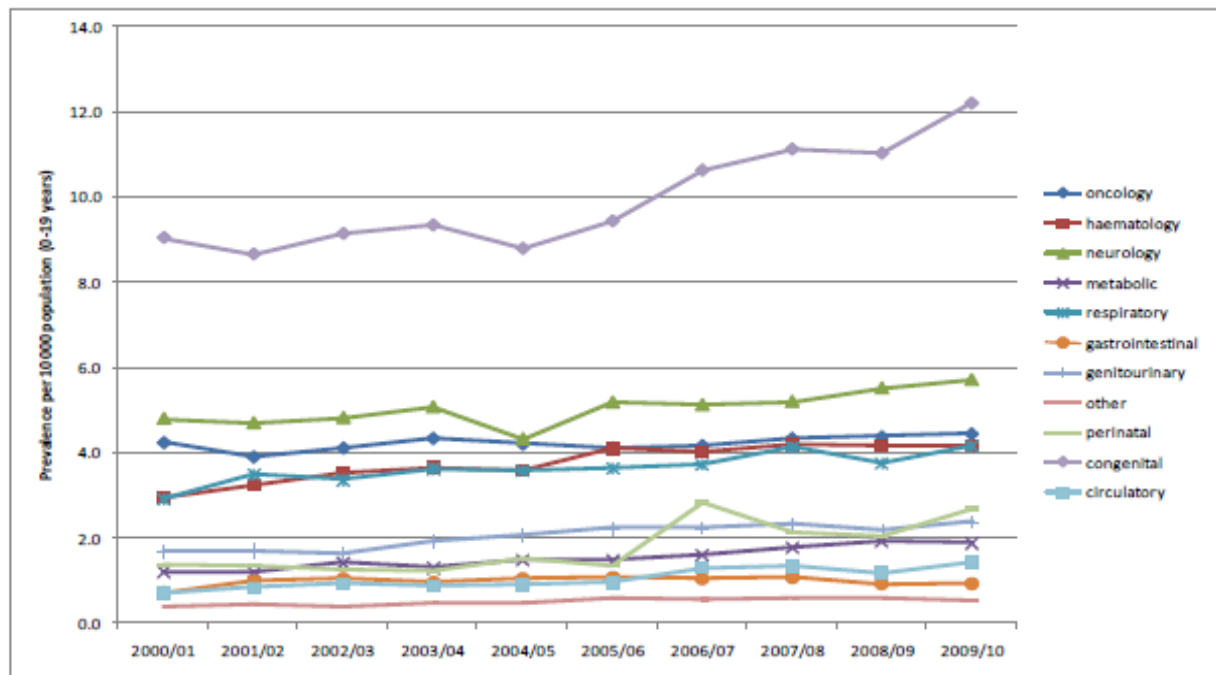


Figure 2.3 The prevalence of life-limiting conditions in children by major diagnostic group in the study region, 2000-2010. (Reproduced with the permission of Fraser). (Fraser et al., 2011b).

As with other regions in England, Table 2.2 demonstrates that the highest increase in prevalence was in the 16 to 19 year old category, which again highlighted the increase in survival times for children with life-limiting conditions. As discussed above these figures are subject to inaccuracies of reporting but they do offer a picture of the trends against diagnostic groups and ages within the region.

In summary the numbers of children and young people with life-limiting conditions is rising. Whilst the highest rate of prevalence is seen in the under one-year-olds (primarily those with a congenital diagnosis), the largest increase in the last decade has been in the 16 to 19 year-old age group (Fraser et al., 2011b). These data have huge implications for transition and adult palliative care services. Whilst historically adult services have catered for adults with cancer nearing end of life, these data would suggest that there will be a generation of young adults with life-limiting conditions who may require palliative care services in an adult setting in the next decade. In addition, services need to be provided which meet the needs of increasing numbers of children under one-year old with life-limiting conditions. It is paramount therefore that studies such as those above

continue to provide regional epidemiological information so that services are planned and delivered to meet local needs.

However, despite global recognition of the need for enhancing the availability and accessibility of paediatric palliative care services, the literature would suggest that in reality there are unmet needs and the uptake of hospice and palliative care services by families with children with life-limiting conditions remains low (Knapp et al., 2011b; Downing et al., 2015; Linton and Feudtner, 2008).

Table 2.2 Number and prevalence (per 10,000 population) of children aged 0-19 years with life-limiting conditions by year and age group in the study region, 2000-2010. (Reproduced with the permission of Fraser). (Fraser et al., 2011b)

		Prevalence per 10000 population																							
	Number of Patients	Total	95%CI			Age <1 YEAR	95%CI			Age 1- 5YR	95%CI			Age 6- 10YR	95%CI			Age 11- 15YR	95%CI			Age 16- 19YR	95%CI		
2000/01	2446	23.4	22.5	24.3	111.6	101.9	121.4	29.6	27.5	31.8	16.3	14.8	17.8	16.3	14.8	17.8	15.7	14.0	17.4						
2001/02	2393	22.8	21.9	23.7	89.6	81.4	97.8	27.6	25.5	29.7	16.8	15.3	18.4	17.5	16.0	19.1	15.5	13.8	17.1						
2002/03	2484	23.6	22.7	24.6	89.7	81.7	97.8	29.1	26.9	31.2	18.1	16.5	19.7	17.2	15.7	18.7	16.4	14.7	18.1						
2003/04	2514	23.9	23.0	24.8	84.6	76.9	92.3	28.8	26.7	31.0	18.7	17.1	20.4	18.6	17.0	20.2	16.1	14.4	17.7						
2004/05	2451	23.2	22.3	24.2	85.5	77.9	93.1	26.7	24.6	28.8	18.8	17.1	20.5	18.3	16.7	19.9	14.9	13.3	16.5						
2005/06	2607	24.6	23.7	25.6	87.6	80.0	95.2	27.4	25.3	29.4	18.6	16.9	20.3	19.2	17.5	20.8	18.9	17.1	20.7						
2006/07	2878	27.1	26.1	28.1	117.9	109.3	126.6	27.8	25.8	29.8	20.5	18.7	22.3	19.7	18.1	21.4	18.2	16.5	20.0						
2007/08	2985	27.9	26.9	28.9	100.4	92.5	108.4	30.8	28.7	32.9	21.2	19.3	23.0	20.6	18.9	22.4	21.2	19.4	23.1						
2008/09	2958	27.6	26.6	28.6	97.7	89.9	105.6	29.2	27.2	31.2	21.5	19.6	23.3	20.4	18.6	22.1	22.0	20.1	23.9						
2009/10	3257	30.4	29.3	31.4	113.6	105.2	122.0	31.8	29.7	33.9	22.7	20.8	24.6	21.8	20.0	23.6	23.9	21.9	25.9						

2.4 Challenges of Paediatric Palliative Care for Health Care Professionals and Parents

From the literature reviewed paediatric palliative care appeared to pose several challenges for health care professionals and parents. This section will first explore the literature that focused on enabling better identification of children who may require palliative care support. In the next section the issues related to the subsequent timing of referral for services are addressed. This is then followed by considering the literature which explored the attitudes of professionals towards paediatric palliative care and hospice services. Following this the challenges posed by the terminology used in the field will be discussed. Finally, the difficulties parents can experience acknowledging their child's condition and the evidence related to determining what parents want from paediatric palliative care services will be explored.

2.4.1 Challenges of identifying children for referral

As discussed earlier the philosophy of paediatric palliative care incorporates care throughout the trajectory of the child's condition. It has been suggested that diagnosis should be the starting point in a process which would identify the potential need for palliative care for many of the children with life-limiting conditions (Ling, 2012a). However, it is also recognised that up to as many as 15% of children do not have a definitive diagnosis (Noyes et al., 2013). Moreover, there are also children with other severe disabilities and complex needs who may benefit from a palliative care approach to their condition. Amongst 420 children (not including neonates) who had died in Wales between 2002 and 2006, 176 different life-limiting diagnoses were identified. This is compared to Hain et al.'s (2013) work which presented a dictionary of over 300 diagnoses, identified and classified as life-limiting or life-threatening conditions in children. Whilst this dictionary which maps ICD-10 codes against the ACT categories has no doubt been useful within research as a tool to define epidemiological data and the population of children needing palliative care, it offers limited help to clinicians wishing to refer to palliative care services. It is evident that the complexities of conditions and diagnoses in children with life-limiting conditions remain a challenge for professionals to know which children to refer for palliative care services (Noyes et al. 2013). An illustration of the relationship over time between curative and treatment options may offer more clarity to

clinicians (Figure 2.3) demonstrating that as a disease progresses the emphasis may shift backwards and forwards between curative and palliative management (ACT, 2009).

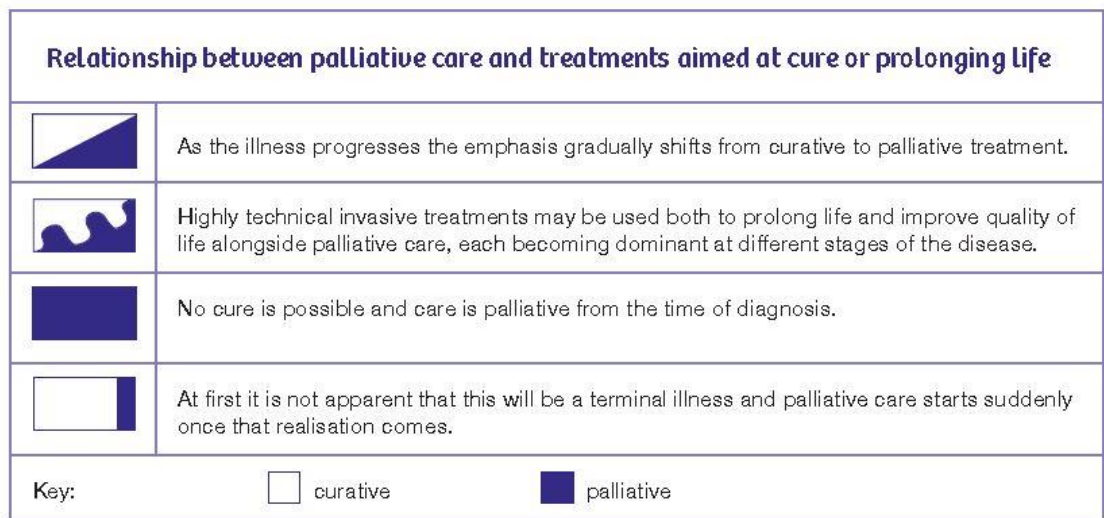


Figure 2.4 Relationship between treatment and palliative care options over time (ACT, 2009)
(Reproduced with the permission of TfSL).

Despite the literature suggesting palliative care should be introduced at the point of diagnosis the uncertainty of disease trajectories means the boundaries between curative and palliative are not completely delineated, and the point at which the concept of palliative care can be introduced to families remains unclear (Hain et al., 2013; Liben et al., 2008). In response to this the Paediatric Palliative Screening Scale (PaPaS scale), a tool to help paediatricians decide whether a referral to palliative care services is appropriate and timely for a child has been developed (Bergstraesser et al., 2013). In the first phase of its development, following interviews (n=7) and focus group discussions (n=11) with clinical leads in paediatric palliative care from France, UK, USA, Canada and Switzerland five domains which could be used to identify children with palliative care needs were identified. These were the trajectory of disease and impact on daily activities for the child, estimated life expectancy, the burden of symptoms, the expected outcome treatment and the associated burden of treatment and finally the preferences of patient, parents and healthcare professionals.

However, in the second phase of testing the validity of the tool amongst a larger sample of experts (n=33), some discrepancies were noticed in results from the first phase (Bergstraesser et al., 2014). Having a life expectancy of fewer than twelve months was

weighted as the highest attribute in deciding whether a child should receive palliative care. This is compared to the first stage of the testing which suggested that a palliative care referral should occur irrespective of prognosis or life expectancy. Secondly the child's or parents' wish to receive palliative care was also weighted heavily. Again this was in contrast to the first stage of testing in which experts suggested that parents would not articulate their wish for palliative care. However, in both these studies (Bergstraesser et al., 2013; 2014) the tool was not tested with patients or their families, rather in the second stage of testing clinical experts used case vignettes to test the identified attributes. It was not possible to determine from the literature the accuracy of the vignettes and whether they mirrored 'real life'. Other studies have also found that symptoms and recurrent hospital admissions were the main factors in deciding whether a child was in need of palliative care services (Wood et al., 2010; Feudtner et al., 2009; Brook and Hain, 2008).

Whilst validity testing of the PaPaS showed variances in results, there is no doubt that a tool which highlights attributes to facilitate doctors' decision making when consulting with parents of children with life-limiting conditions has potential value. However, it is clear that identifying children and deciding at which point in the trajectory of a complex and varied disease pattern it is appropriate to refer a child to palliative care services is a challenge for healthcare professionals.

2.4.2 Attitudes towards referral

Prognostication, described in the literature as a principal role for the doctor, is the skill of being able to identify an illness, predict its path and subsequently offer treatments and suggestions to alter the course of the illness based on their predictions (Glare and Sinclair, 2008; Head et al., 2005). However, many doctors are underprepared and inexperienced in this area, possibly as a result of the lack of formal training (Christakis and Lamont, 2000; Loprinzi et al. 2000). In palliative care the term prognostication is often used to describe the prediction of life expectancy and consequently presents more of a challenge and is something that many healthcare professionals do not want to consider (McNamara-Goodger and Feudtner, 2012; Wolfe et al. 2000).

There are two components to prognostication: foreseeing, that is, the ability by the doctor to estimate the future course of the patient's illness; and foretelling, that is, how the doctor

communicates this prediction with others (Glare and Sinclair, 2008:85). Sharing significant news is not something that is within the scope of the study although it is acknowledged as incredibly important within the field of palliative care. However, the ability to foresee and estimate the course of a patient's illness is fundamental to the initiation of discussions regarding palliative care and can influence and impact on the decisions families make about accessing services, particularly hospices (Head et al., 2005). No published papers could be found specifically concerning whether parents with children with life-limiting conditions want information on life expectancy or not, rather the majority of the literature focused on decision making in advanced care planning and resuscitation. In addition, due to the complexities and the range of conditions it is possible that sometimes a child may not have been given a definitive diagnosis and therefore offering a prognosis is particularly challenging for doctors (Noyes et al., 2013).

Despite the potential positive benefits and advantages that early referral to palliative care services has for patients and their families, there is much evidence to suggest that referrals for palliative care are often made too late for these to be fully experienced (Hain, 2005; Davies et al., 2008; Melvin and Oldham, 2009; Feudtner et al., 2011; Cooney and Atwood, 2013). It is too early to tell whether tools like the PaPaS Scale (Bergstraesser et al., 2013, 2014) and others developed for adults with palliative care needs, such as the Gold Standards Framework Prognostic Indicator Guidance Criteria, the Palliative Performance Scale and the Prognosis in Palliative Care Scores (Gott et al., 2013; Harrold et al., 2005; Gwilliam et al., 2011) will help with decisions regarding the timing of a referral.

Instead it may be more appropriate to develop tools such as the simple traffic light system developed by the team from Helen and Douglas House in Oxford (Harrop and Edwards, 2013). Used with children with a condition in category four of the ACT categories i.e. those with static neurological conditions such as cerebral palsy, the tool lists certain criteria which have been shown to successfully identify when a child is more vulnerable and therefore more likely to be accepted when referred for palliative care services. From the literature it would appear that the tool has only been used in Helen and Douglas Hospice, however it is widely available on the Together for Short Lives website to be used by other organisations. A reasonable assumption would be that similar systems could also be developed to use for children with conditions in the other three categories in the ACT descriptors (ACT, 2009). Despite the suggestion that, regardless of disease trajectory,

there should be early integration of palliative services into the care of children with life-limiting and life-threatening conditions (WHO, 2002; American Academy of Pediatrics, 2000) the literature suggests that, despite recognising the benefits of palliative care services, the complexities of children's conditions continues to make it difficult for health care professionals to decide when such referrals should take place (Davies et al., 2008; Knapp et al. 2009a; Kanpp et al., 2011a). Davies et al. (2008) also found that the most common barrier perceived amongst nurses and doctors (n= 198) was uncertainty in prognosis.

The majority of the evidence pertaining to the perception and attitudes of health care professionals to palliative and hospice services have been conducted by one group in the USA (Thompson et al., 2009; Knapp et al., 2009a, b; Knapp and Thompson, 2012). Within the USA it is a requirement in many states that a clinician certify a patient (adult or children) is within the last six months of life and no longer receiving active treatment before being referred to a palliative care programme or hospice. This means that often referrals to hospices and palliative care programmes are used primarily for end of life care. However, there is evidence that this is changing and certain states like Florida and California (the site of Knapp's work) have waived this notion for paediatric palliative care suggesting that referral criteria may be more akin to those practices in the UK (Knapp et al. 2011a). There are some differences identified in studies from other countries.

In contrast to findings from the USA studies, a study in Germany found that demands of time and lack of reimbursement were the greatest barriers to the provision of paediatric palliative care amongst general practitioners (n=293) (Junger et al., 2010). Furthermore approximately 70% of respondents claimed that uncertainty regarding timing of referral was not a barrier to palliative care. However, in this study more than half of the respondents had no experience of dealing with a child with palliative care needs and for those who had experience, this was very limited and focused mainly on children with cancer diagnoses. Two studies from Australia identified other barriers to referral to palliative care services. The first in Western Australia identified four areas, a lack of knowledge and understanding about what palliative care was, fear of losing control of patients, feeling of failure at not being able to offer cure and a concern about the negative impact of a referral on patients and their families (Melvin and Oldham, 2009). The second in Queensland, amongst a group (n=60) of health care professionals and other

stakeholders found access to palliative care services was an issue because of the rural geography of the country (there were no respite facilities in the state of Brisbane). There was also a lack of awareness and fear regarding referral to palliative care and there was reported to be a lack of experience in palliative care amongst clinicians (Bradford et al., 2012). Whilst these three studies (Junger et al., 2010; Melvin and Oldham, 2009; Bradford et al., 2012) highlight barriers to palliative care they focus primarily on issues faced in their own country and therefore may not be similar to the perception of barriers in the UK.

A study, believed to be the first in the UK, investigated the knowledge, attitude and perceived barriers towards palliative care amongst health care professionals (Twamley et al., 2014). The majority of respondents (response rate 14%, n=132) demonstrated an understanding of the principles of palliative care and just under half of the sample agreed that children with life-limiting conditions should be referred to palliative care services on diagnosis. Despite these findings reported practice was different and referrals were still made late in the trajectory of the child's illness. The dissonance between knowledge and support for palliative care services with referral practice was explained by the results which demonstrated confusion surrounding the term palliative care and the fact that professionals continued to associate it with end of life care. Interestingly in this study the study setting was a large paediatric tertiary care hospital with a well-established paediatric palliative care team. Therefore the assumption that participants in this setting would be fairly knowledgeable lends itself to the continued debate and the disjointedness which still exists between attitudes and understanding. A further challenge identified in the literature is the influence that terminology used in the field has on referrals to palliative care and hospice services.

2.4.3 Terminology used in palliative care

Many of the terms used in the field of palliative care such as: terminal, palliative, life-limiting and life-threatening have different meanings and interpretations to different people, thereby potentially causing confusion for parents and health care professionals (O'Connor et al., 2010). A number of studies have explored perceptions of the term palliative care (Morstad Boldt et al., 2006; Fadul et al., 2009; Miyashita et al., 2008). In the first study, across three paediatric sites (two in-patient and one outpatient) in the USA, first impressions of the term palliative care amongst parents (n=105) and staff (n=79) were negative and results found that the terminology used did not encourage parents to

engage with palliative care programmes (Morstad Boldt et al., 2006). In this particular study programmes labelled as palliative care were compared with those labelled supportive care. Despite describing the term supportive care as vague and indeterminate, results demonstrated that there were negative feelings associated with the words palliative care and parents were more likely to use a programme labelled supportive care. However, when the detailed content of the palliative care programme was shared with both parents and staff, views were more positive, thus demonstrating the lack of understanding regarding the components of palliative care services.

Findings from a second study amongst health care professionals (n=140) in a cancer centre in the USA concurred with Morstad Boldt et al.'s (2006) results and demonstrated negative emotions to the term palliative care compared to supportive care (Fadul et al., 2009). Furthermore health care professionals perceived that using the term palliative care was distressing for patients and contributed to a reduction in hope amongst patients and families. A third study across five regional cancer units in Japan also demonstrated a negative image of palliative care amongst patients, families, doctors and nurses (Miyashita et al., 2008). Miyashita et al.'s study (2008) also suggested that the negative image associated with the term palliative care was a barrier to earlier patient referral to palliative care services.

The evidence suggests that the language used in the field of palliative care clearly has an influence on how it is perceived by patients, their families and health professionals. The term palliative care presents some negative connotations and appears from the literature to be used synonymously with end of life, a term describing the terminal phase of a disease (Morstad Boldt et al., 2006; Fadul et al., 2009). Despite none of these studies (Morstad Boldt et al., 2006; Fadul et al., 2009; Miyashita et al., 2008) exclusively exploring the notion of paediatric palliative care amongst children with life-limiting conditions they reveal important findings on the influence of terminology used in the field. Whilst the debate continues around the terminology used (Claxton-Oldfield et al., 2004) the consensus seems to be that there is no better term to replace it. Recently the term life-shortening has been added to the terminology used in the UK to describe children with life-limiting conditions (TfSL, n.d. (b)) potentially causing more confusion.

Knapp and Thompson (2012) also demonstrated in their work that clinicians believed that families were reluctant to accept palliative care because they perceived it as giving up. This reinforced earlier findings (Davies et al. 2008) which found that families were not ready to access services because of a failure to acknowledge the diagnosis of an incurable condition. The next section will consider the challenges that parents face.

2.4.4 Parents acknowledging their child's condition

A child's illness exerts incredible emotional pressures on parents. Feelings generated have been shown to influence parent's perception of hope and subsequent decisions relating to their child's care (Feudtner et al, 2010). The word hope has multiple connotations; the dictionary definition describes it as an expectation or a desire; and psychologists and researchers have described hope as a need, a concept, a philosophy (Benzein and Berg, 2005). Within nursing, the literature on hope dates back to the 1980's. Hope has been described as a clinical entity, altered by therapeutic interventions (Liben et al., 2008) or temporal, and changing dependent on how a child's illness progresses or deteriorates (Clayton et al. 2005).

Inherent within human nature is the idea that hope depicts living with meaning and a sense of purpose, that better days are coming (Scanlon, 1989; Steinhauser et al., 2001; Benzein et al., 2001). The death of a child disrupts the normal life cycle of events. Whilst parents may have an awareness of their child's condition and potential prognosis, acknowledging that their child's condition may be incurable may be a step too far. Offering palliative care to children who are continuing to receive curative therapy is a challenge for providers of health care and parents because it is perceived as giving up hope for recovery or cure (Brandon et al., 2007; Armstrong-Dailey and Zarbock, 2009). This concept that accepting palliative care support is seen as giving up hope is also seen in adult palliative care studies (Fenz, 2012; Henriksson and Arestedt, 2013; Kirk et al., 2004). Moreover, hopelessness - the opposite of hope - has been shown to contribute to a sense of depression and loss of purpose in life in adults in the terminal stages of their illness (Liben et al., 2008). The uncertainty of the trajectory of a child's condition makes it difficult for parents to make a decision about seeking palliative care services or not. It is vital therefore that providers of palliative care services gets provision right; this means provision that spans the whole journey of the child and meets the needs of the child and family at times when they require it. Different models of palliative care delivery may need

to be considered to cope with demands and these need to be balanced with the needs and wants of parents, children and their families.

2.4.5 Knowing what parents and children want from palliative care services

Whilst patient and public involvement (PPI) as a concept has grown in the last decade, the identification of the needs of children and families requiring palliative care through service user engagement is limited. The review of palliative care services in England (Craft and Killen, 2007) demonstrated inequity of service provision and subsequently the Department of Health Strategy into children's palliative care (DH, 2008) called for a better understanding of local population needs. However, whilst the number of studies in paediatric palliative care has increased substantially in the last decade, there remains a lack of robust evidence to guide the provision of high quality paediatric palliative care. Organisations such as Together for Short Lives have developed pathways and good practice guidelines, but many of these are based on expert opinion rather than the findings of observational studies or clinical trials.

The most significant study in England, known as The Big Study (Hunt et al., 2013) was a collaboration with Together for Short Lives and the West Midlands Palliative Care Network. The overall aim was to explore the extent to which palliative care services in the region met the needs of life-limited children and young people. The study was divided into five strands exploring demographic information, assessment of the effectiveness of the local palliative care network, an economic evaluation of service delivery and patient and public involvement. The second strand of the study, a qualitative, appreciative inquiry of the families' met and unmet needs looked at what was good about services, what could have been better and what the future looked like. Families wanted better communication and coordination of services, more financial support, more respite and more well-being support. These findings reflect those of similar studies conducted globally in the USA, Australia and Switzerland (Mack and Wolfe, 2006; Monterosso et al., 2007; Inglin et al., 2011) which identified the most important factors affecting high quality paediatric palliative care for parents being: financial and practical support for the family in caring for their child; importance of good communication with the child and family; help in decision making and ethical choices; symptom and pain control; coordination of care; and grief and bereavement support.

In response to ascertaining local need a second project in the UK, on behalf of Martin House Children's Hospice (2013) was conducted over a two year period to understand regional provision for children with life-limiting conditions in Yorkshire. Across the region there was a lack of awareness of services, parents reported differing referral criteria and inequity amongst service provision. Short breaks provided at the hospice were identified as a key component in parents' ability to cope with the constant demands of caring for their child with a life-limiting condition. Whilst the outcome of both of these studies (Hunt et al., 2013; Martin House Children's Hospice, 2013) was an assessment of local need which can be used to help evaluate and inform future service delivery they demonstrated that in England inequity of service provision and referral criteria continued. Arguably, the ad-hoc funding of palliative care and hospice services in the UK potentially could be a factor contributing to the difficulties in delivery of services (Hughes-Hallett et al., 2011).

In response to inequities and as a result of the funding review (Hughes-Hallett et al., 2011) a 'palliative care currency' has been developed in England for adults and children. A currency is a way of grouping patients' healthcare needs into units that are clinically similar and have broadly similar resource needs and costs (NHS England, 2015:5). The idea being that a price is applied to each 'currency' and therefore produces a tariff which can be used for funding and commissioning purposes. Within palliative care the currency has been grouped into three 'provider categories': acute inpatients, hospice inpatients and non-inpatient/community settings and four 'phases of illness': stable, deteriorating, unstable and dying (NHS England, 2015). For children the currencies have also been grouped into age categories: less than 1 year, 1-4 years, 5-9 years and above 10 years of age. As an example, the currency labelled as 'CH_4' identifies a child aged 5-9 years who is receiving a package of care within a hospice and is identified as in an unstable phase of their illness. Piloting and evaluation of the currency across a number of adult and children's palliative care services is continuing. One of the benefits of a palliative care currency is that it introduces a common language between providers and commissioners; in theory, services could be designed and developed to ensure best value for patients. Whilst the currency is not mandatory the hope is that organisations like hospices would receive the appropriate funding for the work they do and the care that is delivered to patients. However, until a price is allocated to each unit of currency the realisation of that will not be fully known. Whilst the currency offers a tool which can be used to support

service planning and commissioning there is no evidence as to whether it will affect the mode of delivery for palliative care services.

2.5 Delivery of Paediatric Palliative Care Services

Ambiguity exists in some literature around the use of the term 'models of care'. Often terms such as paradigms, frameworks, theories, philosophies and models have been used interchangeably (Tierney, 1998). In healthcare models of care influenced by evidence based practice and standards are used as tools to shape practice (Davidson and Elliott, 2001). In the UK, the palliative care strategy for children, Better Care, Better Lives (DH, 2008:27) suggested that a model for the delivery of palliative care services in the UK was structured around three tiers (Figure 2.4). At the first tier it was suggested that the provision for palliative care be integrated into all areas of general practice. At this level children and their families would have many of their needs met without referral to any specialist care. This would mean that knowledge of the principles of palliative care would be a fundamental skill for all health professionals both in the hospital and community. At the second tier, core palliative care services would be available and provided by professionals with additional training, knowledge, experience and expertise. Finally at the third tier, specialist practitioners in the palliative care field would provide specialist palliative care services.

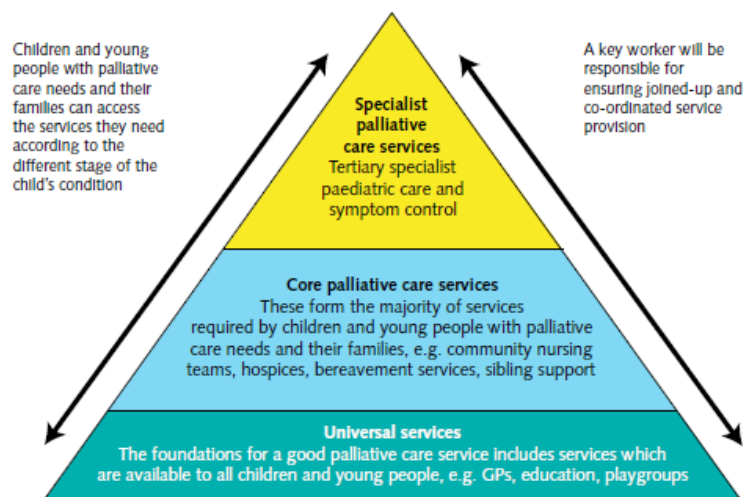


Figure 2.5 Three tiered system of palliative care specialisation (DH, 2008)

Whilst there is consensus as to the level of service that needs to be provided at tiers 2 and 3, there is also the capacity to shape how these are delivered and various models have been described in the literature. The cancer or oncology model was designed around providing care in a specialist centre (usually a tertiary hospital), which also provided outreach. Whilst this model may work well for this group of children the main concern is that many of the children who access palliative care services have co-existing conditions and co-morbidities which need to be managed and therefore a single disease model like the cancer model may not be the best choice. Building on the idea of outreach, a model of paediatric palliative care offering care in the community has grown. Providing care by paediatric multidisciplinary teams has enabled children with a variety of conditions to stay at home, receive the care that they need and die at home if that is their or their family's choice. In many areas of the UK this model has been adopted to offer core palliative care services (level 2), particularly due to the funding which provided teams of 'Diana nurses'.

A third model described in the literature is the use of a clinical network to support the delivery of palliative care in the community (Hain and Wallace, 2008). This is a 'hub and spoke' type model with a central regional specialist paediatric palliative care team for clinical, educational and strategic support, with core paediatric palliative care services delivered by locality teams, paediatricians in general hospitals with an interest in palliative care and general practitioners at the local community level (NHS England, 2013). Nurses in the clinical network model would work across hospice, home, community and acute trust, pulling together all services in a multi-agency manner to meet the best interests of the child. Whilst there is no doubt that offering choice and flexible palliative care services for families from different teams of professionals working together would be beneficial, there is little evidence to suggest that within the UK, amongst the twelve clinical network groups for paediatric palliative care, this is currently being provided. Many of them appear to be functioning as support and consultative structures rather than providing multidisciplinary care via a hub and spoke model as described above (TfSL, n.d. (c)).

Whatever model of delivery is established or currency unit applied, the notion of parallel planning for paediatric palliative care is encouraged and endorsed (American Academy of Paediatrics, 2000; WHO, 2002; ACT, 2009). This integrative approach to care in which

palliative care is offered early at the point of diagnosis and at the same time as other aspects of medical care including possible curative treatments is the focus in the literature (Klick and Hauer, 2010; Mellor et al., 2011). Furthermore, as the literature suggests the provision of respite services is fundamental to supporting parents with children with life-limiting conditions (Hunt et al., 2013; Martin House Children's Hospice, 2013; Whiting, 2014a). However, the evidence is that the provision of respite services is inequitable, inconsistent and insecurely funded (Horsburgh et al., 2002; MacDonald and Callery, 2004; Eaton, 2008; Ling, 2012b; Hughes-Hallett et al., 2011).

2.5.1 Respite at the hospice

Respite has different meanings for different people. As a service, respite offers a range of options including hospice care, care at home, day care and inpatient care. As an outcome, respite usually involves a break from caring and therefore it is generally the carer who is the main beneficiary from the respite (Ingleton et al., 2003:567). However, this has created the notion that the person being cared for is a 'burden' and appears to have influenced the move to referring to respite as 'short breaks' (DCSF, 2010; ACT, 2009). Despite this, respite continues to be a term used and identified with by families, health care professionals and in the literature (Whiting, 2014a, b) and therefore during this thesis the terms respite/respite care/respite service are used to refer to support services that create an opportunity for a child or young person to have a break from their parent/carers and vice versa (DCSF, 2010).

At times caring for a child with a life-limiting condition can place enormous strain on parents (Yantzi et al., 2007; Steele and Davies, 2006; MacDonald and Callery, 2008). The reported benefits of respite for all members of families where there are disabled children is not a new phenomenon (Hoare et al., 1998; Sloper and Beresford, 2006). However, despite being recognised as an unmet need twenty years ago, the evidence suggests that the provision of respite continues to be a problem and the provision of planned and regular breaks from caring for parents as their greatest unmet need (MacDonald and Callery, 2004; Eaton, 2008; Whiting 2014b). The opening of children's hospices could be perceived as bridging a gap in service provision. By developing and offering respite support to families, hospices have been referred to as a 'lifeline' for parents (Jackson and Robinson, 2003:105). One small study in Wales of eleven parents interviewed about their

experiences and views of receiving respite either in a hospice or at home found that providing breaks, however brief, was significant for the parents (Eaton, 2008).

In contrast to adult hospice settings where care delivery has primarily focused on people's experiences of dying and bereavement (Help the Hospices, 2013) the suggestion has been that children's hospices should be a place that caters for the child's whole disease trajectory (Crozier and Hancock, 2012). Palliative care developed from the philosophy of the hospice movement; and consequently the terms palliative care and hospice care have often been used interchangeably (Himilstein, 2006; Crozier and Hancock, 2012). In some areas this has led to the negative views associated with hospices for children and the view held by the public that hospices remain places to die (Steele et al., 2008; Morris, 1998). Despite the growth of hospice services and the advantages that they offer in care (Lindley et al., 2009), it appears from the literature that only small numbers of children with life-limiting conditions are admitted to hospices across the UK and globally (Hain, 2004; Crozier and Hancock, 2012). One study in Florida found that fewer than 11% of children who died and were eligible, received hospice care in the twelve months prior to death (Knapp, 2009c). The results of a second small study with eight parents using a hospice in Canada, found that whilst parent's initial view of the hospice was associated with end of life, something had changed in the lives of either the family or child to force them to see things differently and therefore identify the hospice as a resource for respite (Steele et al., 2008).

Literature pertinent to the experiences of respite delivered by hospices for patients with life-limiting conditions is sparse and focuses mainly on adult studies (Ingleton et al., 2003; Payne et al., 2004; Skilbeck et al., 2005). Two studies (Davies et al., 2004; Champagne and Mongeau, 2012) identified benefits for the parents, siblings and the ill child from receiving respite services at a hospice in Canada. Parents experienced time to themselves, siblings received peer support and parents reported that their ill child was physically and psychologically stimulated from being at the hospice. Two further studies found in the UK explored the perception and experience of users of children's hospices. The first study, commissioned by a primary care trust in Wiltshire in England, asked a purposive sample of parents (n=12) recruited from three hospices in the area, about their referral process to the hospice, their reactions at being referred, and their experiences of using the hospice, (Cooney and Attwood, 2013). Referral routes were not clear and many families accessed

hospices after much emotional stress. Despite this parents reported a good respite experience at the hospice.

The second much larger study used questionnaires and interviews to investigate parents' and young people's perceptions and satisfaction with hospice support (Kirk and Pritchard, 2012). After 108 questionnaires were returned (response rate of 50%), 12 parents and 7 young people were interviewed. All respondents had experience of using the same hospice in the North of England in the last two years and therefore the generalizability of the findings was limited. In common with other studies (Hunt et al., 2003; Robinson et al., 2001) parents reported the value they received from the provision of a break from caring. Parents also valued the family centred and holistic approach to care offered by the hospice. In contrast, the support for hospices has not always been positive. Some authors (While et al., 1996; Skilbeck et al., 2005) have questioned the appropriateness of providing short term respite care in an environment alongside end of life care. Morris (1998) also identified a potential negative impact on a young person's identity of spending part of their childhood in a building identified as being for children who are terminally ill. Although there was some reported apprehension from parents about using the hospice in Kirk and Pritchard's (2012) study, this was dispelled once the parents visited the hospice.

Children's hospices are experienced in caring for the specialised needs of children with life-limiting, life-threatening and complex conditions and consequently are a vital part of any palliative care service. However, the published evidence of their value is sparse. As the numbers of children with life-limiting conditions is increasing (Fraser et al., 2011b) the demands from families for respite is projected to increase. The report 'Dying for Change' (Leadbeater and Garber, 2010) highlighted that hospices in the UK will need to adapt to meet the challenges and opportunities facing them in the next 10-15 years. In response to the report, Help the Hospices established a commission to explore the future of hospice care in the UK. Recognising this issue the commission identified key principles that hospices might use to guide this process (Help the Hospices, 2013). Although the recommendations focus on adult hospices they can also be applied to children's hospices and include the need to work in partnership with local stakeholders, to strengthen leadership in hospices and to ensure that the contribution that hospices make to palliative care is recognised and valued. Indeed the need to establish the contribution that

Woodlands made to palliative care in the region was the reason why the study was sponsored by the hospice.

2.6 Conclusions

Whilst the basic principles of palliative care are common across paediatric and adult palliative care, there are also differences due to the variation, complexity and characteristics of conditions in children and young people. In the absence of a national database (UK) the prevalence of children with life-limiting and life-threatening conditions suggests that many children are now surviving into young adulthood with complex health needs which means that they may require the provision of palliative care services for a much longer time than previously anticipated and may even need to engage in adult services.

Despite many statements that urge early and widespread involvement with palliative care this is not the reality. Studies have concentrated on exploring the reasons for this and determining the barriers that exist amongst parents and professionals. Difficulties with prognostication affects decision making by clinicians in terms of referral and 'correct' timing of referrals to palliative care. Others studies suggest there are barriers in terms of health care professionals' attitudes to palliative care. If as the evidence suggests, the terminology of palliative and hospice care remains synonymous with end of life care, referrals typically will be too few and made late in the trajectory of a child's disease. If this is linked with the evidence that for some parents a palliative care referral may be viewed as giving up hope, then the challenges facing the future of palliative care services are huge (Twamley et al, 2014; Thompson et al, 2009; Knapp and Thompson, 2012; Bradford et al, 2012).

There is no doubt that the United Kingdom has led the way in the development of children's palliative care and hospices. However, as the number of children with life-limiting conditions rises and the age of children surviving increases, the potential demand on hospice and palliative care services will likewise increase. Given the political background, the pressure on hospices, the palliative care reviews, the changing face of health care, changes in commissioning and the need to provide services that meet the needs of families, it is vital that service providers get it 'right' for their population.

Whatever model of care is adopted it needs to be planned, developed, implemented and evaluated incorporating the best evidence and this evidence must be informed by the views and perspectives of children, young people and their families. Although studies have provided some information on the met and unmet palliative care needs of children living in their local regions; West Midlands (Hunt et al., 2013), Humber and Yorkshire (Martin House Report, 2013); Wiltshire (Cooney and Atwood, 2013), it is questionable whether this reflects accurately the needs of families in other areas of the country.

Evidence suggests that the provision of respite support is beneficial for parents, siblings and children with life-limiting conditions but it is unclear whether the hospice should provide this service. Jones and Wolfe (2014:500) question if there is a right way to provide paediatric palliative care and suggest that the way forward is for service providers to design services suited to their local population. The next chapter will present the research methodology and methods chosen for the study to address the question:

How do the needs, experiences, use and acceptability of children's hospice and palliative care services inform new ways of delivering services that would make the most difference to the greatest number of children and families within the region?

Chapter 3 Methodology, Design and Conduct of the Study

In this chapter a detailed account of the choice of the research paradigm, interpretivism, and methodology, constructivist grounded theory (Charmaz, 2014), underpinning the study are presented. Following this the design and conduct of the study are examined, including the strategy for recruitment, methods used for data collection, the ethics approval process and the ethical challenges of the study. The chapter concludes with a description of the process of analysis.

3.1 Philosophical Perspectives

Within the social sciences there is a choice between two distinct approaches to research, qualitative and quantitative. Each of these approaches is underpinned by different philosophical viewpoints. These belief systems, referred to as paradigms by Guba (1990), describe assumptions concerning the nature of reality and what there is to learn (ontology), our knowledge of that reality (epistemology) and the ways of knowing that reality (methodology). Furthermore each researcher brings their individual beliefs and philosophical assumptions to their own research which influences their choice of paradigm, research design and subsequently which methods to use to collect and analyse data (Creswell, 2013; Denzin and Lincoln, 2011). As researchers our ontological and epistemological position falls somewhere between two extreme ends of a continuum with positivism at one end and interpretivism at the other (Denzin and Lincoln, 2011).

Ontologically the assumption within the positivist paradigm is that there is only one reality which exists independent of the experiences of any particular person (Guba and Lincoln, 2005). Epistemologically, knowledge about the world exists in the same way whether it is understood or not. The rationale behind this approach is that research methods are designed around the objective measurement of the phenomenon under question, the belief being that what can be known can be measured. A quantitative methodology situated within a positivist paradigm uses a deductive approach to test theory and hypothesis. Explanations and the evaluation of, phenomena are made using methods of data collection which primarily focus on numeric methods used to generate knowledge, test pre-determined hypotheses, measure and analyse theory and test causal

relationships between variables. The researcher adopts an objective or realist, detached stance with the aim of imposing little bias upon the subject being studied. The focus on the research design is often on recruiting a sufficient sample size to allow statistical analysis of data with the intention that the findings of the study can be generalised across a wider population (Guba and Lincoln, 2005; Denzin and Lincoln, 2011).

Interpretivism, at the other end of the spectrum adopts a relativist ontology in which multiple realities exist, shaped by each individual's own experiences and perspectives. Knowledge emerges as a product of the process of interaction between individuals, whose own experiences and backgrounds influence the meaning they place on events, and situations they experience (Appleton and King, 1997; Schwandt, 1994; Oakley, 2000; Holloway and Wheeler, 2002; Parahoo, 2014). By adopting a qualitative approach, through a process of discovery the researcher explores how individuals make sense of the world they are part of and the meaning that they place on their experiences. In an attempt to understand reality from the perspective of people themselves, the researcher takes an inside or subjective perspective and employs methods that involve engaging and interacting with participants. Through the research process the researcher remains open to uncertainty and ambiguity and is led by the data that emerges. The sample size is often relatively small and the focus of the research is on depth and detail of the lived experience rather than generalisability (Guba and Lincoln, 2005; Denzin and Lincoln, 2011).

Qualitative research is diverse and embedded within the interpretive paradigm and there are different philosophical assumptions that researchers may adopt (Creswell, 2013). As little was known about the views of parents of children with life-limiting and life-threatening conditions towards hospice and palliative care services in the region, the intention was to adopt an exploratory approach. The aim of the inquiry was to understand how experiences in relation to palliative and hospice care were created and given meaning by parents of children with life-limiting conditions. The theoretical underpinnings based on constructivism were the most fitting and consistent approach to facilitate a study design which would capture and address the 'what and how' questions asked in this study.

3.1.1 Constructivist approach

Constructivism acknowledges that rather than simply discovering meaning, individuals construct meanings from experiences of engaging in the world and with people around them. The aim of a constructivist inquiry is to understand and provide an account of the 'constructions' that people hold by encouraging subjectivity and interaction with participants (Appleton and King, 1997; Schwandt, 1994; Guba and Lincoln, 1994; Mills et al., 2006; Creswell, 2009). Constructivism appreciates that there may be multiple views and interpretations of a phenomenon and views are subject to change in response to factors such as time, shifting social and cultural practices. An emergent design is central to constructivist inquiry and for this reason the research occurs within the natural setting, sampling is often purposive and data analysis is conducted using a process of induction.

Having decided on a constructivist approach the next stage was to choose an appropriate methodology. In seeking a methodology that fitted both with the ontological and epistemological position of the researcher and the desire to truly understand parents' perspectives, a methodology which facilitated a subjective approach, enabling the researcher to get close to participants, to engage with them and encourage them to recount their stories and experiences was considered to be the most appropriate for the study. Table 3.1 summarises the methodologies considered as options for the study. Both phenomenology and grounded theory were considered at length particularly variants of these two types; interpretive phenomenological analysis (Smith et al, 2013) and constructivist grounded theory (Charmaz, 2014). The decision taken to employ a constructivist grounded theory methodology is explored further in the next section (Charmaz, 2000).

Table 3.1 Methodologies considered as options for the study (Developed from Creswell, 2013; Smith and Eatough, 2012; Charmaz, 2006, 2014; Thorne, 2008)

	Phenomenology	Interpretative Phenomenological Analysis	Grounded Theory	Constructivist Theory	Grounded	Interpretive Description
Aim of the study	To understand the essence of an experience from individuals who have all experienced the phenomenon. How things appear to individuals through conscious experience of the world in which individuals think, feel and engage with.	The notion that individuals actively interpret events, objects, people.	To generate a general understanding/explanation (theory) of a process, action or interaction shaped by the views of a large number of participants experiencing a phenomenon. Theory developed might help explain practice or provide a framework for future research.	Adopts inductive, comparative, emergent and open ended approach of GT but is much more flexible in nature and less mechanical. Seeks to understand difference and variation among research participants and to co-construct meaning with them. Extends the focus of GT to the socio-cultural context of people's experiences.		To understand experiential clinical phenomena from a pragmatic stance, straddling both objectivity and subjectivity. Provides a framework from which a wide range of options for research design are possible e.g. grounded theory and phenomenology.
Historical background to methodology	Philosophy, psychology	Psychology, hermeneutics phenomenology	Sociology	Social constructivist		Nursing and professional disciplines, applied health research.
Data collection methods	Interviews, observations 10-20 individuals	Interviews. Open ended, how questions. Small numbers participants, emphasis is on describing in depth cases.	Interviews, larger numbers of participants, 20-60 individuals	Interviewing		Whatever methods pragmatically are required to answer question.
Method of data analysis	Analysing units of data searching for meaning and description of the essence/whole phenomenon.	Descriptive and interpretive. Making sense of data through a psychological lens.	Analysis by a process of open coding, selective coding, from local descriptive to more analytical concepts and categories. Theory is grounded in the data from participants.	Uses inductive data to construct abstract analytic categories through an iterative process, process of open coding to focused coding, categorisation and theory building.		Researcher builds on rich description looking for relationships, patterns within the phenomenon described.
Researcher	Preconceptions and presuppositions to be set aside, researcher questions and reflects on their influence of the research process.	Researcher tries to understand what it is like to be in the shoes of the participants, they have a dynamic, critical, probing role.	Researcher actively moves back and forth through the data, actively making notes of their thoughts and what the data is saying.	Does not adhere to the notion that in GT the researcher is a neutral observer or value free. Acknowledges subjectivity and the researcher's involvement in the construction and interpretation of data.		The researcher and participants interact to influence one another.

3.2 Research Methodology - Constructivist Grounded Theory

Grounded theory is an approach to research developed by Glaser and Strauss (1967) which systematically collects and analyses qualitative data for the purpose of generating a theory about the phenomenon in question that is 'grounded in the data' (Corbin and Strauss, 2008; Charmaz, 2014). Soon after the publication of their seminal text "Discovery of Grounded Theory" (Glaser and Strauss, 1967), the divergent epistemological viewpoints of Glaser and Strauss became more apparent, and grounded theory as a methodology took different directions. Glaser reflecting more of an objectivist focus based on his underlying positivist epistemology, and Strauss, who reflected more of a pragmatic philosophy based on the symbolic interactionist view of human behaviour (Strauss and Corbin, 1998).

Influenced partly by Strauss, Charmaz (2000) developed an approach to grounded theory, underpinned by a constructivist approach. Whilst Charmaz (2014:12) advocates an inductive, comparative, emergent, open-ended approach to research more in keeping with the traditional definition of grounded theory (Glaser and Strauss, 1967), there are several areas where her approach differs. In keeping with constructivism she acknowledges that multiple realities exist, and, in order to understand and study varying views, researcher subjectivity is encouraged and the importance of interaction between researcher and participants is emphasised (Charmaz, 2006, 2014). Her methodology supports a constructivist epistemology where due to new experiences, knowledge is constantly evolving for people and as a consequence the research methods adopted should focus on discovery and creativity. Data collection and analysis occur at the same time, an iterative process of moving back and forth between the data and emerging analysis means that each informs the other (Bryant and Charmaz, 2007).

In the traditional approach to grounded theory Glaser (1992) advocated that the researcher should approach a study with as few predetermined thoughts as possible, remain free from bias and maintain an objective stance when analysing the data. In contrast to this, Charmaz (2014) encourages a process of reflexivity whereby throughout the research process the researcher engages in active reflection, adopts an attitude of self-awareness and explores their values, beliefs and biases (Eatough, 2012). This doctorate has been a journey of learning and discovery for me as a researcher and at many times through the process, I would describe my head as feeling 'muddled' and 'chaotic'. Having

an attitude of self-awareness means that not only was I conscious of the personal assumptions I brought to the research process but also, by critically engaging with the research process, I could reflect on decisions and make any necessary adjustments.

Glaser (1992: 31) argued that bias is introduced into the research process by the process of reading and searching the literature prior to data collection, a view not held by Charmaz (2014). Charmaz (2014) argued that there were benefits from engaging with the literature in the subject field, suggesting that the literature had the potential to stimulate thinking and contributed to the theoretical sensitivity of the researcher. In this study as identified in the previous chapter, a background literature review was performed and this influenced the development of the research question and the construction of the topic guides used for data collection.

Reflexivity is also fostered in the comparative method of data analysis as the researcher scrutinises the data again and again (Charmaz, 2008:402). During the research process a reflective journal was used to maintain a record of how my abstract thinking developed. It also enabled me to maintain field notes during data collection, keep an audit trail of decisions made, problems encountered and resolved during the research process. Finally, Charmaz (2014) describes how the researcher is integral in producing a narrative concerned with interpretation and abstract thinking as the meanings and actions that have been constructed by participants are described.

Having presented the rationale for selecting grounded theory underpinned by constructivism as the most appropriate approach for this study, the next section will describe the design of the study and how focus groups and semi-structured interviews were the most appropriate methods to facilitate a dialogic approach to data collection.

3.3 The Research Design

Research needs to be well designed and organised; preparation is fundamental in this process and for this reason there was an extensive scoping period prior to writing the study proposal. The account below demonstrates the process that took place to engage with key players in the region working in the palliative care field to gain their support and buy-in to the study, gain an appreciation of their understanding around the broad

issues to be explored and sets the scene for the context of some of the decision making shaping the design of the study.

Additionally, being aware of the financial commitment from the hospice to fund the study was an ongoing *self*-motivating factor to develop, manage the study and produce something relevant and of value. However, whilst the study needed to be of clinical relevance to the hospice and influence service development where appropriate across the region, it was important that any potential tensions or pressures from the hospice, the funding organisation, were managed appropriately and sensitively. Therefore, a steering group was established to help guide the conduct of the study; this group met quarterly. The group was made up of twelve members, with internal representation from Woodlands board, local paediatric palliative care experts, two parent representatives, academic supervisors and external independent representation from Together for Short Lives and NHS England. Consultation and frank discussion with this group added to my confidence in the veracity of the study. There was also the ability to discuss any tension experienced with my supervisors. However, because of clarity established in initial development meetings, despite the hospice having an investment in the project, there was also an awareness of the value and need for academic freedom for the study. Consequently, as the researcher I experienced a remarkable degree of personal autonomy and independence during the study, as can be seen, for example, with the decision presented below about the methodological focus of the study.

3.3.1 Scoping of the project

Over a three month period, October to December 2013, the researcher conducted face-to-face meetings with professionals throughout the region who had an interest in palliative care. In addition to various staff from Woodlands, including their senior management team, medical team and Board of Trustees, meetings were held with the Head of Care at one of the hospices bordering the region, the Chief Nurse from one of the community trusts, a nursing lead from one of the clinical commissioning groups, a community paediatrician, various members of the paediatric palliative care network group and a representative from the charity Together for Short Lives. Arguably, at this stage there were expectations particularly from the Board of Trustees to produce work which was more of a quantitative nature. Drawing on previous experience as a clinician, there was an element of trust which existed between myself and several members of the trustee

board which meant that sharing the results of the scoping exercise and negotiating outcomes was more manageable. As a result, the decision to progress with a qualitative study and the question formulated for the research study was:

How do the needs, experiences, use and acceptability of children's hospice and palliative care services inform new ways of delivering services that would make the most difference to the greatest number of children and families within the region?

From the scoping it was also apparent that there were two separate groups of potential participants, those who used a hospice and those who did not. The intention was to conduct a two phase qualitative study; phase 1 would use focus groups as a data collection method with hospice users and phase 2 would use in-depth semi-structured interviews with non-hospice users. Whilst the design is represented as a linear process, data collection and analysis occurred simultaneously throughout phase 1 and phase 2. The next section will detail the challenges to recruitment that meant some changes to the design were necessary.

3.3.2 Challenges of recruitment

Difficulties in recruiting participants into palliative care studies is not a new phenomenon and is described in the literature (Hinds et al., 2007; Stevens et al., 2010; Tomlinson et al., 2007; Knapp et al., 2010; Liben et al., 2014; Bluebond-Langner et al. 2015). One of the main ethical challenges and debate surrounding palliative and end of life research is the view that it involves accessing a vulnerable population (Casarett, 2003; Duke and Bennett, 2010) and inviting recruitment into a study is seen to be placing extra burden on potential participants (Fine, 2003). Conversely, others argue that avoiding research in this population is disadvantageous as their views, experiences and needs are necessary to add to the evidence base for appropriate management and care in the field (Mount et al., 1995; Jubb, 2002; Casarett, 2005; RCN, 2009).

Another challenge in recruitment is gatekeeping (Duke and Bennett, 2010). Gatekeeping usually occurs when a professional or family member makes a decision that, due to the burden or potential distress that it may cause the participant, it would not be in the best interests of a person to be invited to participate in research (Hudson et al., 2005; Seymour et al., 2005; Ewing et al., 2004; Bluebond-Langner et al., 2015). During recruitment

researchers often rely on the goodwill and cooperation of health care professionals to identify and make the initial approach to potential participants. Whilst professionals recognise a need to support research, the view that participants with palliative care needs are vulnerable, causes professionals in their role as patient advocate to worry that participation in research would potentially cause anxiety and upset to their patients (Hinds et al., 2007; Wolfe, 2012; Bluebond-Langner et al., 2015). Consequently professionals decide to either invite certain individuals or not invite potential participants at all and bias is introduced into the selection process (Bluebond-Langner et al., 2015). The evidence suggests however, that rather than finding participation in research distressing or a burden, parents and children find it a positive experience, value the opportunity to tell their stories and believe that their participation will help others (Wolfe, 2012; Buckle et al., 2010; Stevens et al., 2010; Mickelson et al., 2006; Hynson et al., 2006; Hinds et al., 2007; Steele et al. 2014).

Therefore strategies to recruit and encourage participation need to be well thought out. In this study an opt-in strategy was employed. Whilst evidence suggests that an opt-in strategy can contribute to low response rates and may fail to capture the full range of views on an issue (Hewison and Haines, 2006; Ward et al. 2004) it is the approach recommended by ethics committees in order to reduce any potential for coercion to participate in studies by the researcher. In both phase 1 and 2 an opt-in strategy was adopted for recruitment and it was only after an expression of interest had been received that the researcher was made aware of the identities of and had any contact with the families. Furthermore, to ensure there was no overt 'persuasion' to take part, no rewards or incentives were used in the study except reimbursement of travel expenses. However, the option of childcare for parents was offered to enable parents to participate.

3.3.3 Sampling strategy

A purposive sampling strategy based on the concept of selecting participants who, because of their first-hand experience, could inform and provide information and understanding related to the phenomenon of palliative and hospice care was employed (Teddlie and Yu, 2007). In the context of this study the participants were the parents of children with life-limiting or life-threatening conditions. From the outset of the research study it was decided that children would not be recruited into the study. Although children and young people have the right to express their views, wishes and feelings; many children with life-

limiting and life-threatening conditions are cognitively impaired and lack the communication skills to make informed choices. The decision not to invite children to participate was not taken lightly but took into account the sensitivities surrounding hospice and palliative care and also acknowledged that to do justice to engaging children with a range of communication impairments would be beyond the scope of this study.

3.3.3.1 Inclusion and exclusion criteria

Participants in this study were healthy adult volunteers who had been invited because they had a child with a life-limiting or life-threatening condition as defined and categorised by the Association for Children's Palliative Care, (now known as Together for Short Lives), (ACT, 2009):

- Category 1: life-threatening conditions for which curative treatment may be feasible but can fail e.g., cancer, cardiac anomalies;
- Category 2: conditions in which there may be long phases of intensive treatment aimed at prolonging life but premature death is possible e.g., Cystic Fibrosis, Muscular Dystrophy;
- Category 3: progressive conditions without curative treatments e.g., progressive neuromuscular conditions; and
- Category 4: conditions with severe neurological disability which may cause weakness and susceptibility to health complications but are not considered progressive e.g., severe cerebral palsy.

The study inclusion criteria were:

- Parents of a child, young person 0-25 years who had a life-limiting or life-threatening condition and/or continuing care needs as defined by the ACT (2009) criteria;
- Families lived in the named region;
- Phase 1 families were known to receive services from Woodlands Hospice;
- Phase 2 families were known to receive services from one of the collaborating children's community/palliative care teams;
- Parent/s were able to give informed consent; and
- Parent/s agreeing to take part in the study were able to speak English.

An upper age limit for the child of 25 years was set as this was the upper age limit for referrals to the hospice; and was also in keeping with the National Special Educational Needs and Disability agenda (DoE, 2011). Whilst it was recognised that restricting the study to parents who spoke English may have limited the study, the inability of the researcher to speak other languages and the absence of finance for interpreters and translation meant all interviews and focus groups were planned to be in English. In addition there was the concern that using an interpreter whilst exploring feelings and perspectives in such a sensitive area had the potential to introduce misinterpretation into the data; and that because of the potential sensitive nature of the topic area the researcher would not have been able to fully support families where English was not their first language.

The exclusion criterion was:

- Parents who had a child who was known to have died in the last year.

It was important to make sure that the specific criteria by which parents could be included or excluded from the study were understood by those staff inviting potential participants. Therefore prior to commencing both phases of the study the researcher met with staff to outline the inclusion criteria and exclusion criterion, answer any questions and discuss the paperwork that would be sent out to potential participants.

3.3.4 Ethical considerations

All research is underpinned by the ethical decisions made regarding the design, conduct and reporting of the research (Duke and Bennett, 2010). Undertaking any research involves ethical risks and benefits and many challenges for the researcher and participants. As the researcher I had a responsibility to ensure that participants were empowered to make their own autonomous choice about whether to participate in the study, and that they were given the full facts of the study including any potential risks and benefits, reassuring them of confidentiality and anonymity throughout the course of the study and in the dissemination of findings and that their consent was given.

In a recent review paper of paediatric palliative care (Liben et al., 2014) the authors suggested that, in studies involving paediatric palliative care, ethics committees are either

reluctant to sanction projects or make the process for approval difficult because of their concerns that the research will increase stress on what is perceived as already burdened families (Casarett, 2003; Duke and Bennett, 2010). Therefore for this study the best way to address potential ethical issues was to prepare for them as fully as possible and consider a wide range of potential scenarios. Advice received from submitting the research proposal to various ethics committees helped thinking and preparation in this area. In addition, both the steering group and users at the hospice helped in the wording of participant information sheets and invitation letters. Whilst there was the need to be open about the intention of the study, there were concerns that parents may not have heard some terminology before, such as palliative care or life-limiting conditions, and that it may have put potential participants off replying to invitations. For this reason the participant information sheets were worded to acknowledge complex needs rather than palliative care needs of the family (Appendix 2 and 3).

The following section will describe the process undertaken to achieve ethical approval to conduct the study and the ethical principles which were considered to ensure the study progressed within a research governance framework.

3.3.4.1 Gaining approval for the study

The process of acquiring ethical approval was complex and required considerable effort, owing primarily to the two phase approach of the study and recruitment strategy. As De Montfort University were acting as the co-sponsor for the study, but having the overall responsibility for the conduct of the study and providing indemnity insurance the first step was to obtain approval from the Faculty of Health & Life Sciences Research Ethics Committee. Following submission to the committee (March 10th 2014) clarification was sought on various issues regarding recruitment to the study, potential risks to participants and researcher, assurances regarding data storage, confidentiality and anonymity of participants. One particular area which was helpful was the suggestion of a defined procedure should a participant become distressed or upset during the interviews. As a result a process was set up for referral to counselling services and signposting for other support agencies should participants require it. Following resubmission with amendments, the study gained favourable approval (5th May 2014).

Following this a process of ethical approval had to be undertaken with the NHS Research Ethics Committee (NRES) using the Integrated Research Application System (IRAS). Following submission, clarification was sought by the committee on the process to be followed should I, as a health professional, be made aware of any concerns or disclosure of poor practice during interviews and visits to participants' houses. This information was included in participant information sheets (Appendix 2 and 3) and favourable opinion was gained from the regional NRES (18th June 2014).

At the same time it was necessary to seek approval from the seven NHS Research and Development Departments (R&D) of the respective organisations who would act as Participant Identification Centres (PIC's) for recruitment in phase 2 of the study. In order to minimise the potential for any error or delay in consideration, prior to submission initial contact was made with the research leads from the seven areas to request information regarding their application process and any extra paperwork that they would require. Negotiating access and seeking NHS Trust R&D multisite approval was a highly complex, time consuming and cumbersome piece of work, particularly due to the lack of uniformity across all seven PICs. Figure 3.1 demonstrates the complexity of the process and the time taken (seven months) to gain final approval for the study.

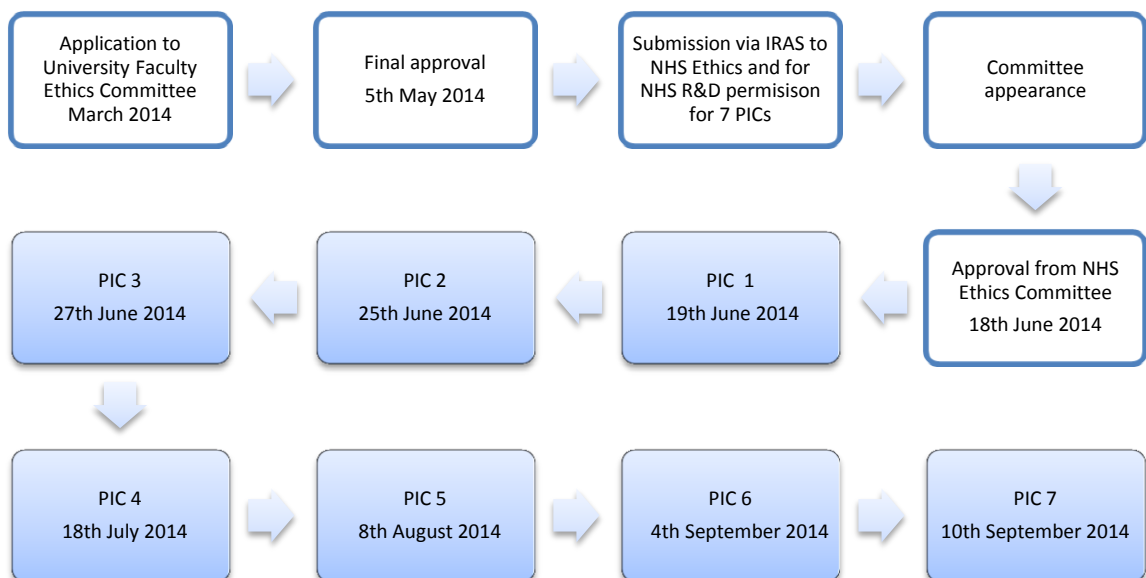


Figure 3.1 Timeline for process for ethical approval

3.3.4.2 Consent procedures and confidentiality

Consent in research is the process whereby someone voluntarily decides to participate in a research project based on full disclosure of sufficient information to be able to weigh up risks and benefits of the research (Polit and Beck, 2004; Casarett, 2003). Participants received information packs (invitation letters: Appendices 4 and 5; and participant information sheets: Appendices 2 and 3) specific to each phase; and prior to any contact from the researcher. Consent also includes the right to withdraw from the study; this was highlighted in consent forms. However, participants were informed that following withdrawal it may not be possible to remove information already supplied in the study. All participants were asked for their written consent for the appropriate phase of the study (Appendices 6 and 7). Two copies of consent forms were created; one for the participant and one for the study file. It was agreed with the ethics committees that a minimum of 48 hours was needed from receiving the invitation packs to gaining the participant's consent and conducting the interview. In most cases participants had much longer than this. Recognising that informed consent is an on-going process meant that, prior to commencing the focus groups and interviews reaffirmation of consent was sought and gained from the participants.

All recordings were downloaded immediately after the interview and stored on a password protected database as per policies placed on the researcher via the university. The files on the digital recorder were then deleted. Participants were assured that any data would have their name and address removed (anonymised) and pseudonyms were used so that they were not recognised. In addition, participants agreed as part of their consent that anonymised quotes from their data could be used and that these would not include details that would identify them or their families.

As per university policy it was explained that any personal data (address, telephone number) would be kept for 6 months after the end of the study so that a summary of the findings could be forwarded to participants (unless the researcher was advised that they did not wish to be contacted). All other data would be stored for ten years in a secure location within the university, accessible only by members of the research team. After this time, as per the university policy, data would be disposed of securely.

3.3.4.3 Risks of the study

The processes that are in place via research ethics committees are there to safeguard and protect participants from harm and ensure research is conducted to the highest quality and standards (DH, 2005). Therefore during the planning stage a careful assessment of risk versus benefits was made. Table 3.2 presents a summary of the potential risks identified during the planning stage of the study and the strategies put in place to minimise these.

Table 3.2 Potential risks identified during planning stage, strategies employed to minimise risk

Issue	Potential risk	Strategy to minimise risk
Participants are parents of children with a life-limiting conditions.	Topics addressed during interviews which are emotional, sensitive and potentially upsetting for parents.	<ul style="list-style-type: none"> • Information leaflets identified potential for upset (Appendices 2 and 3). • The option to uptake counselling and support services available to participants identified (Appendix 2, 3 and 10). • Participants able to stop interviews and withdraw from study at any time. • Researcher will follow up with a phone call to participants, if they agree, two days after participation in focus group or interview to ensure they have support if required. • The researcher is an experienced children's nurse who has worked with vulnerable families in the field of palliative care, she is experienced in dealing with sensitive and difficult situations.
Time is precious and known to be limited for parents of children with life-limiting conditions.	Burden of time to participate.	<ul style="list-style-type: none"> • Flexible recruitment, offering choice in times for interviews and focus groups, during school, evenings and weekends available. • Choice of location, child care offered, travel expenses reimbursed.
The nature of life-limiting conditions may involve deterioration or death of child.	Parents may have difficulty or fail to recognise the inevitability of their child's death which is then brought to their attention by participation in the study (Tomlinson et al 2007).	<ul style="list-style-type: none"> • Information sheets highlighted that participants free to withdraw from study without giving a reason. • Sensitive approach to participants, careful choice of words, mirroring language parents used when talking about their child. • Consultation with parents on the steering group meant that wording was acceptable, "parent friendly", promoted freedom of choice and reassurances that participants could change their mind to participate at any time.
Disclosure of information.	Identification of poor practice or professional concerns.	<ul style="list-style-type: none"> • Participant information leaflets highlighted action to be taken should any poor practice or safeguarding issues arise (Appendices 2 and 3)
Risk to researcher.	Lone working and conducting interviews in participants' homes. Emotional labour for researcher.	<ul style="list-style-type: none"> • Policies and procedures for lone working were followed. • Clinical supervision and counselling services available at hospice if required. • Support of two supervisors experienced in undertaking research of this nature, who were experienced nurses.

3.4 Data Collection Methods

In keeping with a constructivist methodology, a dialogic approach to data collection was required. This section will describe the theory underpinning the chosen methods, focus groups and face-to-face interviews, and how these were conducted. In phase 1 focus groups were used to collect qualitative data from the population of parents of children with life-limiting conditions living in the region accessing services at Woodlands. As a data collection method, focus groups aimed to offer a safe forum for participants to interact and express ideas, explore differences of perspectives and opinions and add meanings and constructs to their individual knowledge base (Krueger and Casey, 2014; Millward, 2012). In phase 2 of the study, in-depth semi-structured interviews were conducted with parents of children with life-limiting conditions living in the region who did not use any services at the hospice, but were known to palliative care health teams in the community.

3.4.1 Phase 1- Focus groups

Focus groups have been used as a method of data collection in market research and the social sciences from as early as the 1920s (Millward, 2012). More recently they have become a popular means of exploring patients' experiences of healthcare and illness (Krueger and Casey, 2014; Owen 2001; Rabiee, 2004; McLafferty, 2004; Webb and Kevern, 2001). As a research method, focus groups have been described as a form of group interview that capitalises on the interaction and discussion that takes place between participants whilst exploring a specific set of issues (Kitzinger, 1994; Freeman, 2006; Barbour and Kitzinger, 2001). Participants are encouraged to talk to one another, to question and exchange comments on each other's experiences, and to explore and clarify ideas and attitudes (Krueger and Casey, 2014; Kitzinger, 1995; Duggleby, 2005; Freeman, 2006). Quite simply, Millward (2012:413) describes them as "a discussion-based interview that produces verbal data generated via group interaction".

Krueger (1994:44) comments that focus groups are also particularly relevant when insights are needed into complicated topics with multifaceted concerns, such as paediatric palliative care. Also from a pragmatic point of view, focus groups were used because they presented a method of data collection which would enable an understanding of the attitudes and experiences of a group of participants from the hospice, to potentially

generate a wide range of responses from participants; and to collect deep, rich data in a relatively short time (Barbour, 2007; Rabiee, 2004).

3.4.1.1 Participant recruitment phase 1

For phase 1, parents of all of the children who were using the services at Woodlands were sent an invitation letter (Appendix 4) and a participant information sheet (Appendix 2) from the Director of Care at the hospice inviting them to express an interest in joining a focus group. By recommendation from the ethics committee to manage recruitment numbers, invitations were sent out in batches of 50 at a time, (total, n=258) to families selected randomly from the database by the Director of Care. Both parents, as appropriate within each family, were invited to attend the focus group although prior consultation with parents on the project steering group suggested that probably only one parent would attend. Parents who were interested were asked to respond directly to myself and provide a telephone number and/or e-mail address for contact purposes. Once expressions of interest were received potential participant(s) were contacted and any questions they had about the study were addressed.

Knowing that six to ten participants is an ideal number and takes into account the potential for participants to fail to turn up on the day (Krueger and Casey, 2014; Burrows and Kendall, 1997; Webb and Kevern, 2001; Bloor et al., 2001), the study was designed with the intention of recruiting eight participants to each focus group. Bloor et al. (2001) suggest that groups can work successfully with as few as three and as many as fourteen participants, however, there is a risk in small groups of limited discussion compared to large groups which can be hard to facilitate and frustrating if participants get little opportunity to speak. Recognising that recruitment to palliative care studies is difficult (Hinds et al., 2007; Stevens et al., 2010; Tomlinson et al., 2007; Bluebond-Langner et al. 2015) and that parents with children with life-limiting conditions lead very busy lives (Whiting, 2014a), parents were offered the choice of attending a group locally.

A distinct feature of focus groups is the ability to collect data based on the interaction between participants (Krueger and Casey, 2014) therefore it was vital that participants were comfortable with the setting that they were meeting in. Anticipating that running focus groups at Woodlands had the potential to place parents in a difficult position due to lack of anonymity, and to facilitate choice, the study was designed with the intention of

running six groups in various locations across the region. Each location was visited by the researcher beforehand and assessed for its suitability to run a group in terms of car parking facilities, a quiet comfortable, private space within which to conduct interviews, toilet facilities, and the ability to make refreshments.

Once verbal consent to participate was given the parent's preferred location for attending a focus group was discussed. Many of the parents stated a preference to attend a group at the hospice. Six focus groups were conducted during the period July to October 2014; four held in the hospice and two in alternative locations. All groups were made up of parents whose children used services at Woodlands and they were not preselected because of any other characteristic other than meeting the inclusion criteria for the study and their choice of date and geographical location. Despite contacting participants a few days before to remind them of the group time, offering options in different geographical locations, times which suited parents and the option of childcare, fewer participants attended each focus group than expected. Table 3.3 details the number of participants who verbally consented (recruited) to attend a focus groups compared to those who attended on the day. Whilst the response rate for phase 1 of the study was 13.6 % (n=35) the number who attended was 21 (8%).

Following completion of six groups, three participants who were unable to attend their allocated focus groups expressed an interest to contribute to the study. Because of geographical limitations and their time restraints it was not possible to run another focus group. Therefore following discussion with supervisors and submission of a 'notification of amendment' to recruitment for phase 1 to the ethics committee all three parents were subsequently invited and agreed to take part in one-to-one interviews. In summary, a total of 21 participants (four male) took part across six focus groups and three participants (one male) took part in an individual interview.

Table 3.3 Numbers of recruits compared to participants (Phase 1)

	Number of recruits	Number of participants
Focus group 1	8	6
Focus group 2	5	3
Focus group 3	4	3
Focus group 4	6	3
Focus group 5	7	4
Focus group 6	5	2
Individual interview		3
Totals	35	24

3.4.1.2 Conduct of the focus groups

Following identification of their preferred venue, participants were sent via the post a consent form (Appendix 6) together with a letter confirming details of focus group date, timing and location. Being mindful of the time pressures placed on many families with children with life-limiting conditions, childcare was offered to participants to cover the period of time they were involved with the focus group. Participants were asked to bring the written consent form with them on the day of the focus group session.

Building on the theories that suggest that focus groups follow broad topics, drawing on the literature and working with the steering group several core areas were identified that would guide the focus group (Appendix 8), and aid the researcher to facilitate discussion about a particular area without leading the group (Millward, 2012; Fontana and Frey, 2000). This allowed for similar areas to be covered in all focus groups, conversations to be stimulated or focused as necessary but also fostered the flexibility to tailor questions and the order of them to suit the group and the conversations generated. Since the steering group had reviewed the topic areas for discussion, it was decided not to pilot a focus group. However, during the first group conducted, and with the permission of all the participants, a colleague from the university sat in so as to be able to offer the researcher reflection on the processes used, questions asked and the researcher's role as facilitator within the focus group.

All participants consented to the recording of conversations. As a token of respect for each other, participants were asked to speak individually and not speak over one another. Participants were reminded that the group would last no longer than one and half hours, but could be paused at any time if a participant requested it so. Refreshments (tea and coffee) were provided. During focus groups the researcher made short notes on what she believed to be important non-verbal interaction and cues between participants. These were then later added to the transcript of the focus group, for example:

Jane (pseudonym) [participant] getting very agitated, body language, head down. [Field note, Focus group 1].

To enable recognition and allocation of voices on the recordings, and to try to facilitate a more relaxing environment and put participants at ease each focus group commenced with four general questions:

- Please tell me something that you want me to know about your child?
- Describe to me the services that you are currently using at the hospice?
- How long have you been using these services?
- What other services are you currently using?

These questions were also used to set the context in terms of the availability and the experience of using other services throughout the region and the level of support that parents were receiving. Whilst it was never the intention to introduce topics into discussions that would upset participants, it was important for the researcher to be aware of the sensitivity of discussing a child's palliative care needs and the potential for some parents to experience distress. In one group one particular participant was getting very agitated as another participant was persistently referring to death. The researcher managed this sensitively by waiting for a break in conversation, acknowledging the contribution, and then posing a different question to the group. In another group when a participant became upset recalling their experiences, the audio recording was stopped and they were given time to recover and regain composure. Assurances of continuing discussions were received from all participants before restarting the interview.

Each group was different and therefore group dynamics very much affected the facilitation style used by the researcher. When group dynamics worked well, participants engaged in interaction which was both complementary and argumentative. At times, however, the

level of communication between participants was low, although there were many nods of agreement that led the researcher to believe there was an appreciation of shared experiences. In one group with only three participants it was necessary to adopt a more active role and actively probe and guide discussion. In other groups a direct approach was taken to engage those participants whom appeared to be finding it difficult to contribute, for example by looking directly at one participant, resulted in an opportunity for her to share her story:

[Banu (pseudonym), participant] "you're looking at me"(giggles) [Extract from Focus group 3].

Generally the participants were very supportive of each other and many times there was a lot of appropriate humour and laughter as the excerpts below taken from transcripts demonstrate:

Stuart (pseudonym) - "me and my partner can actually go out for a meal one day maybe, on our own, in a restaurant, wow" !, (lots giggles);

Researcher - So, in terms of mums and dads, what could the hospice offer you that you've not been getting?

Ann (pseudonym) - "Alcohol in the fridge. A bar" (lots laughter) [Extract from Focus group 1].

Group interaction is not just about consensus of experiences, differences in perspectives are equally important. In one group there was one parent who had a more negative view of the hospice compared to other parents in the group. However, rather than cause any imbalance in discussions there was a real appreciation and respect within the group of the differences, which led to further discussions and sharing of information. Balancing research and professional roles can also be difficult. At times boundaries become blurred. In one group it was evident that one parent was still very angry and bitter about having a disabled child; I recognised that I wanted to offer her advice on accessing some counselling so, at the end of that particular focus group, I reminded all participants of the system in place should they feel they needed support. In phase 1, only one participant asked for further support. This was from a desire for information about services for her child rather than as a result of participating in the study.

Lunch was provided following the morning sessions and this enabled participants to share some time with each other. Following each focus group, I wrote a reflection on how I felt

the group went. The extract below, from my notes made after the first two focus groups, demonstrates the diversity that exists between groups and the impact that has on the researcher:

"I have spent so much time in preparation and organisation and it's so hard to recruit and get people to come. The first group when six turned up was good but this second group was poorly attended and I feel really fed up. Conducting the first focus group was easier, flow was good, interaction was good, and participants were all involved. This second one was so much smaller, some people didn't turn up and so there were only three of us. I have twenty two years as a qualified nurse but I feel inexperienced and suddenly aware that I am entering unknown territory for me. I feel out of my depth". [Project journal note, Focus group 2]

As mentioned earlier three parents, after failing to attend their focus group, expressed an interest to be involved in the study. The three interviews were carried out at their individual homes at a time to suit the participant, following the same topic areas used in the focus groups. The interviews were also a useful forum to check and clarify patterns that were emerging from the analysis of the focus groups in phase 1. Whilst focus groups and interviews share many common features, there was less pressure on the researcher to facilitate conversation in the three interviews. All three participants had requested to be involved in the study and therefore readily participated in the interview. On reflection it was also easier for the researcher in the interview setting to introduce sensitive topics like the term palliative care. However, unlike a group setting the individual interviews did not present the option for participants to challenge each other and justify their remarks.

3.4.2 Phase 2- Semi-structured interviews

Interviewing involves a direct exchange, usually verbally, between the researcher and the participant. Smith et al., (2013: 57) describe the qualitative interview as a "conversation with a purpose", in which the interaction which takes place between researcher and participant, enables the participant to share their stories and experiences regarding a particular phenomenon for the purpose of answering the research question (Wahyuni, 2012). Parents from the steering group had highlighted to the researcher that there was the potential in the research that some parents who were recruited may have difficulty or fail to recognise the inevitability of their child's death. Therefore for those parents who were being recruited into the second phase of the study with little or no experience of a

children's hospice, one-to-one interviews were identified as being the best data collection tool to sensitively explore the areas of palliative and hospice care. In keeping with constructivist grounded theory, collecting data by interviews also enabled the researcher to interact with participants, explore the accounts of their individual experience and explore new areas of interest that they raised (Charmaz, 2014). Knowing that interviews can be structured, unstructured or semi-structured dependent on the way and order in which participants are asked the same questions (Breakwell, 2012) the decision was taken to conduct semi-structured interviews for this phase, using a guide detailing topics of interest to pursue and guide the researcher (Appendix 9), (Smith et al., 2013).

3.4.2.1 Participant recruitment phase 2

In order to gain access to parents for phase 2 who were not using hospice services across the region, help from local community children's nursing teams was required. The paediatric palliative care network operating in the region offered access to teams who were committed to palliative care services, lead nurses from seven children's community health teams covering the area were identified and agreed to support the study. In research terms this meant that these teams would act as Participant Identification Centres (PIC's), identifying potential participants from their caseloads. Twelve types of children's palliative care services were identified as providing various and differing services across the region, two from acute tertiary hospitals, six based in district general hospitals, three in community trusts and one hospice, with an additional children's hospice just outside the borders of the region (Public Health England, 2015). Using only seven teams out of 12 possibilities to help with recruitment was a potential limitation for the study and may have meant that there were children and families who may not have been given the option to participate. However, the complexity and time taken to gain ethical approval from each individual NHS Trust R&D department (section 3.3.4.1) meant that it would have added to the pragmatic challenge to have gained access to all teams or service providers. For this phase of the study the teams were selected to give a geographical spread across the region.

In order to prepare fully for applications for ethical approval and to gain further 'buy in' prior to the start of the recruitment process the researcher met with all the teams to brief them about the project, ensure they were fully informed of the study aims and objectives and answer any of their questions. Each team were asked to select from their caseload parents of children with life-limiting conditions, who met the eligibility criteria for the

study. Initially each team were given twenty invitation packs, more were available if requested. All teams were very supportive and felt that they would be able to identify potential parents to invite them to be recruited to the study. Team members were asked to give parents a brief verbal introduction to the study and then give them an invitation pack containing a letter of invitation and participant information sheet (Appendix 5 and 3). Parents were able to respond to the invitation by telephone letter or e-mail directly to the researcher for further information.

Every month the researcher emailed a given contact in each team to discuss any concerns and gain an update about how many packs had been given out, this also served as a prompt for them to continue to think about the identification of further potential participants. Although there is little guidance in the qualitative literature as to the best choice of sample size, the aim was to recruit at least three participants from each of the seven teams (n=21), for the purpose of gathering data across a geographical spread of the region. As the phase progressed, the reality of the difficulties in recruiting became very clear. Concurring with a study by Ewing et al. (2004), despite constant reminders of the study to the community teams recruitment success remained disproportionately low compared to the effort that went into it. After six months 48 parents had been invited to participate. As teams had invited all the parents they felt were suitable and the opt-in strategy did not permit the researcher to follow up on invitations, recruitment was stopped. From November 2014 to April 2015, eleven interviews were conducted with a total of 3 fathers and 11 mothers of 11 children. By request three interviews were conducted with both the child's mother and father present. The interviews ranged from 32 minutes to 60 minutes.

During the interview process in phase 2 it also became clear that half of the participants recruited were not actually non-hospice users. Instead these were families who were either undergoing referral to a hospice, had undergone a 'look and see visit' or had experience of using a hospice outside of the region, consequently this group of participants were labelled 'hospice aware'. In total, seven parents were hospice aware (HA) and seven were non-hospice users (N-HU).

Table 3.4 Numbers of parents invited compared to participants (Phase 2)

	Number of parents invited	Number of participants
PIC 1	2	2
PIC 2	15	4
PIC 3	6	3
PIC 4	14	3
PIC 5	3	0
PIC 6	8	2
PIC 7	0	0
Totals	48	14

3.4.2.2 Conduct of interviews

In preparing for interviews it was important that potential participants knew what to expect in terms of time commitment and to check what they understood by the term interview. Upon receiving a positive response potential participants were contacted by the researcher and a time to visit the parent at home was arranged in order for written consent to be obtained. On the first visit the researcher clarified that the parent(s) had read the participant information leaflet (Appendix 3) and had the opportunity to discuss the content. Any questions they had regarding the study were addressed. Knowing that interviewing parents in pairs had the potential for different information to be received from interviewing them individually, it was decided that if both parents expressed an interest to be recruited they were given the choice of being interviewed together or separately (Astedt-Kurki et al., 2001; Gysels et al., 2008; Taylor and de Vocht, 2011; Radcliffe et al., 2013). A follow-up appointment was then made for the interview to be conducted.

With interviews it is often trust and rapport with a participant which encourages and empowers them to reveal insights about their experiences (Nunkoosing, 2005, Fontana and Frey, 2000). Participants were given the choice of being interviewed at home or at the hospice to ensure that they felt as comfortable and relaxed as possible. All participants chose to be interviewed at home and the interviews were conducted in the living area of

the family home. On arrival to all of the family homes the researcher accepted the offer of a drink, which gave time to establish rapport with the participant, offered an opportunity for some general conversation and for some insight regarding their child to be gained. When organising the interviews they were set up wherever possible, to fit in with participants' schedules; the majority were conducted during week days and school hours; although two were conducted in an evening and two at a weekend. Prior to starting the data collection parents were thanked for agreeing to participate, offered assurances of confidentiality and anonymity, confirmed their on-going consent to participate and checked if they had any questions. With the full written consent (Appendix 7) of the participant their interview was digitally audio-recorded.

The preparation, planning and construction of questions is vital to the flow of an interview. General questions were used at the beginning to encourage participants to become more relaxed and comfortable in speaking to the researcher (Charmaz, 2014). Open-ended questions were used to encourage participants to disclose as much or little information as they chose. Follow up probing questions such as "tell me more about that" or "how did that make you feel" were used to keep the conversation flowing, to explore concepts that had arisen during the interview or help the researcher draw participants into the conversation (Rubin and Rubin, 2012; Nunkoosing, 2005). At other times probes such as encouraging sounds or gestures were used by the researcher to encourage participants to expand more. It was also important to avoid questions which were double barrelled, leading, contained double negatives or jargon (Breakwell, 2012). However, whilst mindful not to use any medical or nursing jargon, questions were asked which related to the participant's understanding of terminology and words used in the field of palliative care. Whilst trying out questions and getting feedback in a pilot interview is a useful way to determine whether initial questions are sufficient to elicit a response or whether they are unclear or too complex (Breakwell, 2012), a decision instead to test the questions with the parent representatives on the steering panel was made.

Using a guide as an aide-memoir enabled the researcher in the first few interviews to be more relaxed, and therefore to concentrate and listen more attentively to what was being said rather than worry about the next set of questions. As interviews continued and new ideas were presented from other participants, the guide was revisited and refined. Using the interview guide also helped with the phrasing of questions when exploring more sensitive areas such as end of life care. However, on reflection, when listening to

recordings and reading through transcripts I recognised my limitations as a novice researcher. On several occasions I missed opportunities to explore areas further; over time my technique improved and I became more confident.

Each interview began with asking participant(s) to share some basic demographic information about their child, including age and diagnosis; the services that they used and the current support they were getting. This was used as an opportunity to allow parents to disclose as much information about their child as they wanted, to help them relax into the conversation and to offer reassurances that the researcher had no prior access to information regarding the family. This was also essential in establishing some rapport with participants and engendering a sense that the researcher was interested in all that they had to say. Each interview concluded with asking the parents if there were any further issues or information they would like to discuss. Reflective notes were made as soon as possible following each interview. The excerpt below is the researcher's reflection following the interview of two parents who had requested to be interviewed together. During analysis this excerpt added to the reassurances that the experiences of parents who has used an alternative hospice, other than Woodlands, were comparable.

*"This was such an interesting family, it was a joint interview with mum and dad. They just wanted to keep sharing their experiences, they kept talking and talking. Dad got upset halfway through the interview and admitted feelings that he had not shared with his wife. The interview was stopped and he excused himself, returning ten minutes later and asked for the interview to be resumed. I really enjoyed sitting listening to them, they had so much experience of different services. What was really good was they had used a different hospice across the border of the region and so much of what other parents had said about Woodlands they concurred at *[hospice place]. [Project journal note, Interview with Josie and Pete].*

3.4.3 Support offered to participants

Interviews have the potential to trigger emotional experiences for participants. Although it was never the intention to upset parents, there was the possibility that sensitive issues would arise, and/or that the study had the potential to cause parents to reflect on their child's condition and/or to confront their own emotions regarding palliative care and end of life. Although the researcher had many years of experience working with families with children with complex and palliative care needs in community and acute settings, her experience as a researcher was limited. In order to respond appropriately to participants

who may have become upset because of the interview process it was vital that strategies were in place to manage these (see Table 3.2 in section 3.3.4.3). At the start of both focus groups and interviews participants were also reminded that discussions could be paused or indeed stopped should they not wish to continue. If questions were asked and it was felt that a participant was uncomfortable then by observing their non-verbal behaviour a decision to either gently pursue or back off from further exploration was made.

At the end of the interview in both phases all participants were offered written details of how to contact counselling and other support services should they have felt that they needed to discuss any issues following the interview (Appendix 10). As co-sponsor of the PhD, Woodlands offered all participants access to their support team, (a team of qualified nurses and counsellors), if they wished. Participants were also offered a follow up contact from myself two days after they had participated in the study to ensure they had support if required. Two parents, one from each phase, asked for access to the support team at the hospice.

3.4.4 Reflection on data collection methods

Duggleby (2005) proposes that the combination of focus groups and individual interviews can be advantageous and complimentary for research. Using these data collection methods in phases 1 and 2 of the study contributed to a more comprehensive understanding of the experiences of both hospice and non-hospice users as participants' perspectives of the same phenomenon were compared. By adopting an iterative process, the preliminary themes identified from the focus groups helped determine the most pertinent questions and topics to be covered and explored further during individual interviews in phase 2.

As I conducted interviews and reflected on my experiences it struck me that not all distress is bad and there were certainly times during interviews when it was obvious that discussions, despite causing some upset for parents, were encouraging them to think about the future and their needs. Indeed in one of the joint interviews a father admitted to his wife that he had never expressed his feelings in a particular area to her before and found a huge sense of relief in taking part in the interview as it gave him an opportunity and time to reflect and express his thoughts.

Throughout the data collection phase, as I listened and reflected on the experiences and perspectives of the participants, I felt touched by the time they had given up to speak to me. Before starting this research I thought I knew and understood what families went through with children with life-limiting conditions. I soon realised that all I had ever caught - even as an experienced and skilled children's nurse - was a glimpse of their reality and that actually I had no idea of the complexities of their lives, their struggles, their isolation, and their hopes for the future. There were many times after the interviews where I left a home with what I described as a "heavy heart". To some extent that feeling encouraged me to continue with the PhD; the heightened recognition that there was a need for more research in this field, to enable families to tell their stories, for us as care professionals to listen, to learn and to move forward. Figure 3.2 is a diagrammatic representation of the study that was conducted and the number of participants recruited to both phase 1 and 2 of the study. The next section will discuss the approach taken in the analysis of the data produced in phases 1 and 2 of the study.

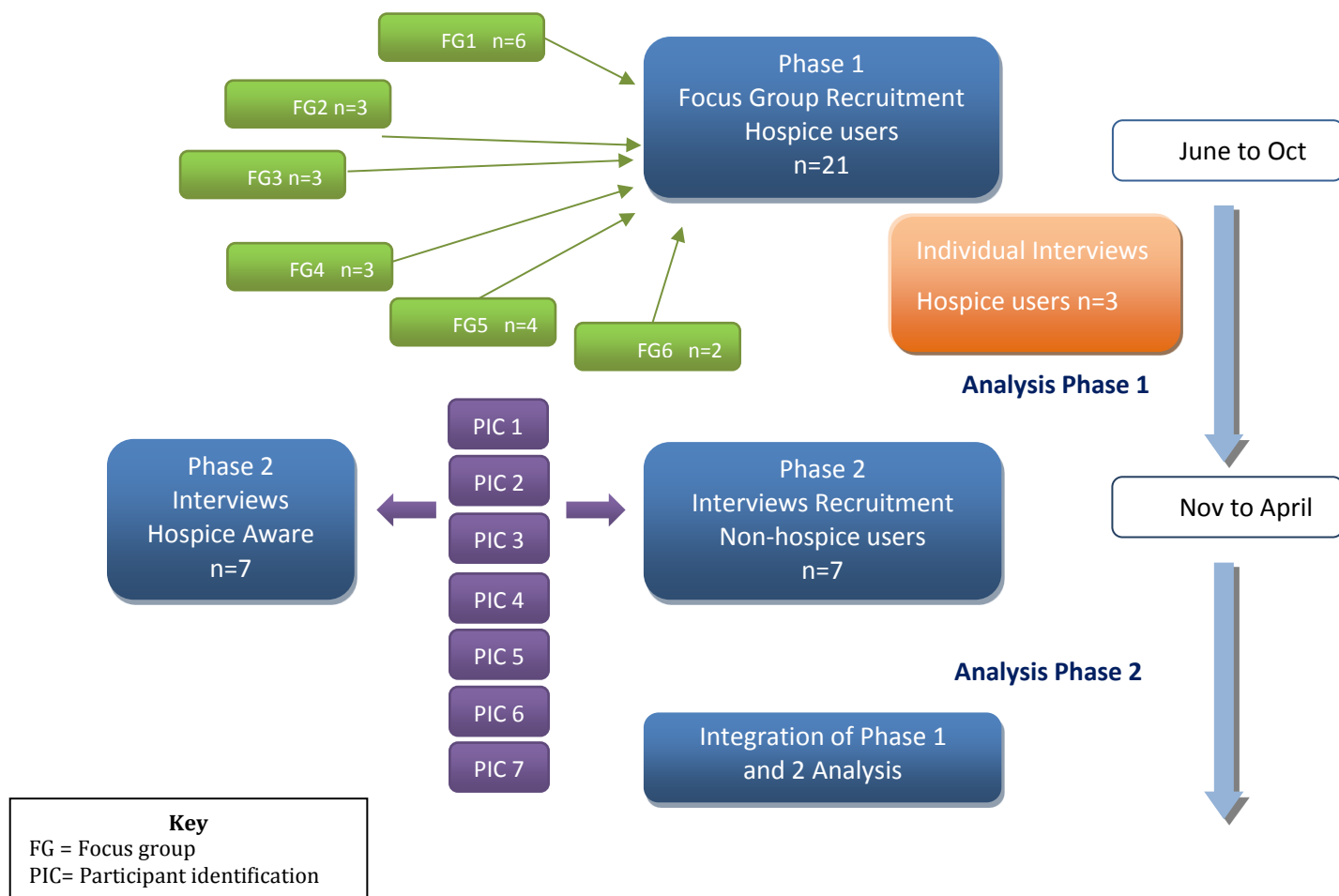


Figure 3.2 Design of the study showing participants recruited to both phases.

3.5 Data Analysis Process

The study was about exploring participants' perspectives and experiences of hospice and palliative care services. With qualitative data analysis a process occurs whereby data are firstly managed and secondly analysed. The challenge for the researcher is to deal efficiently and systematically with the vast quantity of unstructured data collected: in this study, 252 A4 pages of transcript were generated. At the same time as coding and condensing the data the researcher must maintain the richness and context of the data. Analysis was by no means a smooth process. In this section the process of data analysis using Charmaz's (2014) approach is explained. In describing the process of explaining and exploring the data collected the choices made and the difficulties experienced are reflected on. Demographic details of the participants recruited to the study are detailed to offer some context to the analysis. This section will conclude by presenting a pictorial overview of the three major conceptual themes that emerged from the findings which will form the focus of the next three findings chapters.

3.5.1 Demographic details of participants recruited to the study

In total, three groups of parents participated in the study, twenty four participants were hospice users (HU), seven were non hospice users (N-HU) and seven were hospice aware (HA). To protect the anonymity of participants, letters were first used to identify them, however, when later presenting the narrative account of each theme the use of letters was quite impersonal and were therefore replaced with pseudonyms. All other identifiable data were removed from the transcripts, pseudonyms were also used to identify other names or place locations. Table 3.5 identifies participants for each phase of the study. To give some context in which parents are commenting the age band and ACT disease category for each child is detailed (ACT, 2009). Due to small sample sizes in the study and the range and rarity of conditions possible, in order to protect anonymity the children's specific diagnosis has not been revealed.

Table 3.5 Participants in the study by age and diagnosis category

Pseudonym of parent	Pseudonym of child	Age band of child	ACT Category for diagnosis of child's condition
Hospice User (HU) n=24			
Ria	Will	11-15	2
Doreen	Luke	20-25	1
Stuart	Sam	1-5	3
Laura	Jasmine	6-10	4
Jane	Ellie	1-5	4
Ann	Jarryd	16-19	2
Sharon	Rob and Rick	Child A - 16-19	2
		Child B - 16-19	2
Amy	Keith	6-10	3
Mark	Todd	11-15	3
Linda	Bill and Ben	Child A - 11-15	2
		Child B - 11-15	2
Banu and Amir	Kas	6-10	4
Emma	Lewis	1-5	3
Charlie	Niamh	16-19	4
Julie	Siobhan and Tim	Child A - 20-25	2
		Child B - 20-25	2
Jill	Sonya	20-25	3
Penny	Tanya	16-19	4
Suze and James	Nick	20-25	4
Mona	Ahmed	20-25	2
Fran	Chloe	11-15	3
Katie	Paul	11-15	2
Shona	Rory	1-5	4
John	Matt	16-19	4
Hospice Aware (HA) n=7			
Ruth	Martha	11-15	3
Abi	Simon	11-15	2
Josie and Pete	Conor	6-10	2
Felicity	Maddie	6-10	4
Hannah	Daniel	1-5	4
Verity	Jess	6-10	4
Non-Hospice User (N-HU) n=7			
Bernie	Joshua	16-19	4
Larai and David	Lucy	1-5	3
Pauline	Fred	1-5	4
Caitlin	Peter	11-15	4
Edna and Andrew	Thomas	1-5	3

Figure 3.3 is a diagrammatic representation of the range of ages of children whose parents participated in the study across the three participant groups. In phase 1, 18 of the 25 children represented were above the age of 11 years. In phase 2 most of the children were younger, below the age of 11 years.

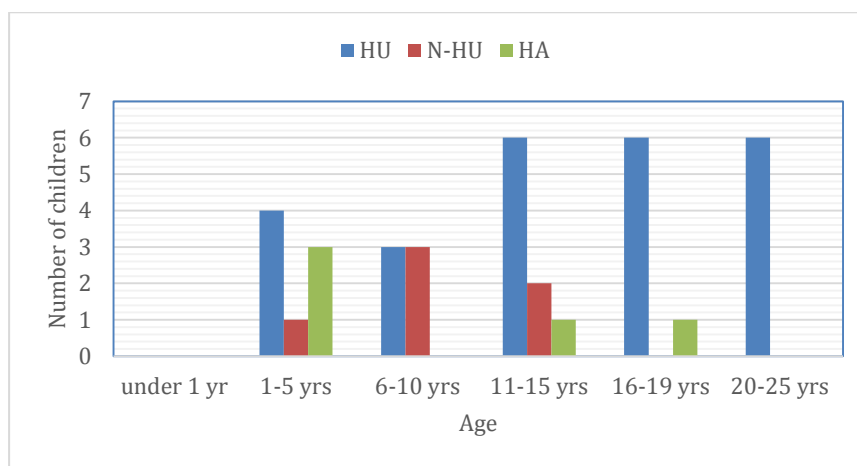


Figure 3.3 Ages of children of the parents who participated in the study

Looking at diagnoses groupings (section 3.3.3.1) of the 36 children represented in the study, one had a diagnosis which met the criteria in ACT category 1, twelve met the criteria for category 2 (a muscular dystrophy), nine for category 3 (progressive neuromuscular conditions) and fourteen for category 4 (severe neurological disabilities).

In phase 1 the average length of time that the child had been attending the hospice was 8 years, (range of 2 to 20 years) demonstrating the experience of the parents with hospice services. On average families were travelling 19.6 miles (median of 19 miles) to come to the hospice for respite (range of 1-58 miles). In addition to hospice services, parents across the three groups were using a variety of other services funded through health or social services, such as community nursing teams, respite facilities in other locations, carers from various nursing agencies or personal assistants supplied through social services. There was however a wide variation in access to services, some parents received help for four nights a week, whilst others were allocated 4-6 hours help per week, allocation for personal assistants ranged from 5 to 25 hours per week. For three of the 38 parents their only source of help was from the hospice, and four parents were receiving no help from any services.

3.5.2 The process of data analysis

Based on the constructivist grounded theory approach underpinning the qualitative phases of the study, Charmaz's (2014) approach to data analysis was adopted. Grounded theory analysis involves cycles of data collection, coding, memo-writing and theory building as categories emerge and are developed from the data. It is a constant iterative process of moving back and forth across the data, whilst simultaneously stopping and asking questions of the data collected (Charmaz, 2014); the process is characterised by three stages; initial coding, focused coding and finally conceptual analysis and synthesis leading to the development of categories and themes (Charmaz, 2014). Whilst Charmaz's staged approach to analysis is a more simplified form of the analysis processes suggested by both Glaser (1992) and Strauss and Corbin (1998) the components of original grounded theory remain central to the analysis process; (constant comparison, memo writing, theoretical sampling, theoretical sensitivity and saturation) and will be referred to below. As a method of data analysis the approach is grounded and consequently driven by the data and original transcripts of the participants. This approach of going beyond the process of simply describing participants' views, to trying to identify and interpret the way in which meaning is experienced and constructed; and the underlying ideas and assumptions that participants have is compatible with the constructivist paradigm.

Gathering data and preliminary analysis were conducted concurrently first in phase 1 following each focus group interview and then in phase 2 following each semi-structured interview. Whilst analysis in the strictest form did not occur between each interview or focus group, recordings were listened to and transcriptions reviewed to gain an overall sense of the findings. Topic areas that arose were then explored more fully in subsequent focus groups and in phase 2 of the study. This process of data informing further data collected is fundamental to grounded theory methodology and is referred to as theoretical sampling.

The section below will describe the stages of the in-depth analysis which took place following phase 1 and then repeated with phase 2 of the study. Although described as a linear process all stages of analysis took place simultaneously as data continued to be collected, and the researcher continually went back and forth between stages comparing and contrasting codes and conceptual ideas which were being constructed. The data from each of the three groups of participants identified as HU, N-HU and HA was analysed

separately and then finally integration and cross analysis of the data sets were conducted to determine the final themes for the study.

3.5.2.1 Transcribing

All participants in both phases consented to their interviews being recorded and downloaded. Transcribing began immediately following each interview. In order to optimise accuracy in this process, the ideal scenario would have been that the researcher personally transcribed all of the interviews. However, after completing transcription of the first focus group, recognising that the process was particularly time consuming and laborious, further transcribing was outsourced to a known reputable transcription service. In the brief the researcher asked the transcriber to simply type verbatim the recording. The transcriber was very efficient and returned each interview within 48 hours. This meant that the researcher was able to check the interview transcripts whilst the interview was 'fresh' in their mind.

Once transcripts were received, they were checked back against the original audio recordings for accuracy. Utterances like laughing and pauses, and any field notes made during interviews were added to the text. There were several occasions when the transcriber reported 'inaudible', this was mainly due to the use of medical jargon or place names that she was unfamiliar with. By reviewing the text and recordings a deeper appreciation for each of the interviews and the data was achieved, and the process of becoming familiar with the data began. In itself, correcting the transcripts whilst time consuming, was obviously much quicker than doing all the transcription myself and, on reflection, it meant that I was more alert, ready to listen and concentrate on the recordings, and immerse myself in the data produced. Knowing that one of the potential challenges facing transcription of focus groups is distinguishing participants' voices, the introductory questions used to collect demographic details were a useful voice check for the transcriber.

During and following each focus group, notes and reflexive comments were made, memos of initial thoughts on what was occurring from the data were added, and details of what to explore further in subsequent focus groups were made. At various stages during the process of analysis the researcher returned to the transcripts and repeated reading and

re-reading of the original transcripts helped to identify and extract any new elements, to discover variances and to check the credibility of the findings.

3.5.2.2 Initial coding

Codes, categories and concepts are the building blocks of grounded theory. Initial coding was the first stage in the analysis of the data and forms the foundations from which eventually a theory will develop. Charmaz (2014:111) describes a code as a segment of the raw data such as a thought, action, feeling, event which is labelled to capture the meaning and context of the text. Coding provides the tools for interrogating, sorting and synthesising transcripts and enables the researcher to condense large amounts of data into smaller manageable units (Charmaz, 2014). During this stage the researcher examines transcripts line by line and begins to break up the data by asking questions such as 'What are the data/participants saying?' and 'How does this view compare to another in the data?'

Initial coding of the interview transcripts was carried out strictly in order that the interviews had been conducted. Interview transcripts were first uploaded into a software package, NVivo (QSR International Pty Ltd. Version 10, 2012). The text from each transcript was systematically considered line by line, codes were developed (referred to as nodes in the programme) and data was added to each node. During initial coding Charmaz (2014:120) suggests that the researcher remains 'open' as they interact with the data, building codes and discovering meaning. In the labelling of nodes the researcher used both her own words and, in an attempt to stay as close to the data as possible, at times used 'in-vivo codes', the words of the participants, for example, "*where I'm meant to be*" and "*majority rather than minority*". Within NVivo it is possible to open a transcript and review it alongside the developing index of nodes (see Figure 3.4).

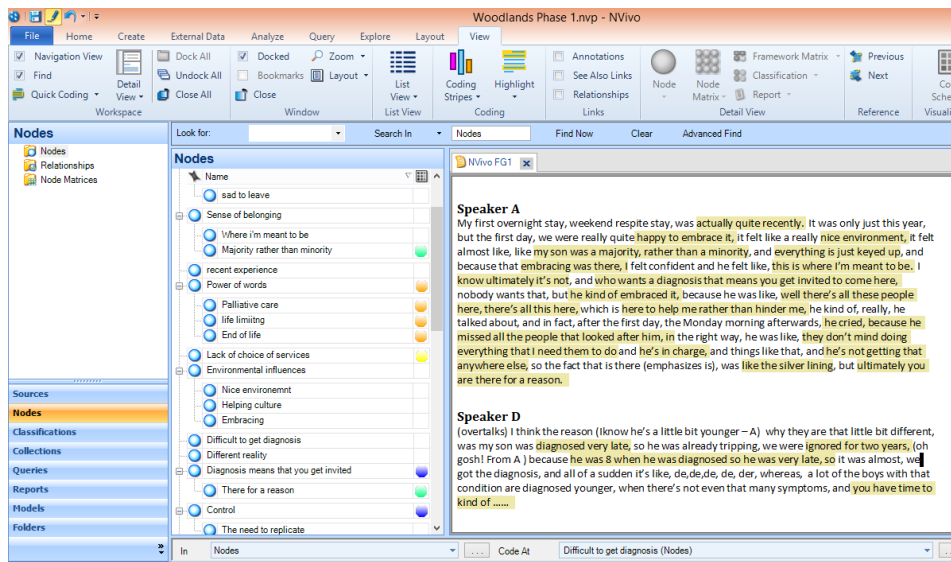


Figure 3.4 Snapshot from NVivo of transcript and developing index of nodes

As analysis continued new nodes were created. Within NVivo there is the ability to label each node with a description of its scope, this also served as a reminder of the researcher's initial thoughts. For example: one of the initial nodes from focus group 1 was 'sense of belonging' and was described as belonging to or being part of somewhere. As coding for each focus group continued data were organised under the node headings, it was also possible within the programme if necessary to code data to one or more nodes. The process of coding continued throughout the first focus group until a long list of nodes was created. Coding then continued systematically across the entire data set in phase 1, forming new codes (nodes) or adding to existing codes dependent on the adequacy of the code label to capture the intrinsic meaning expressed in the coded text.

Memo writing is another fundamental component of the grounded theory process of analysis and describes how the researcher records what they believe is happening in the data, their thoughts, feelings, analytical hunches and insights that relate to the interpretation of the data (Charmaz, 2014). Noerager-Stern (2007:119) describes memos as the 'mortar which sticks the building blocks of the data together'. As the data was coded it was constantly interrogated. Within NVivo a record of dated memos were stored under a project journal file. Figure 3.5 shows an example of a memo made.

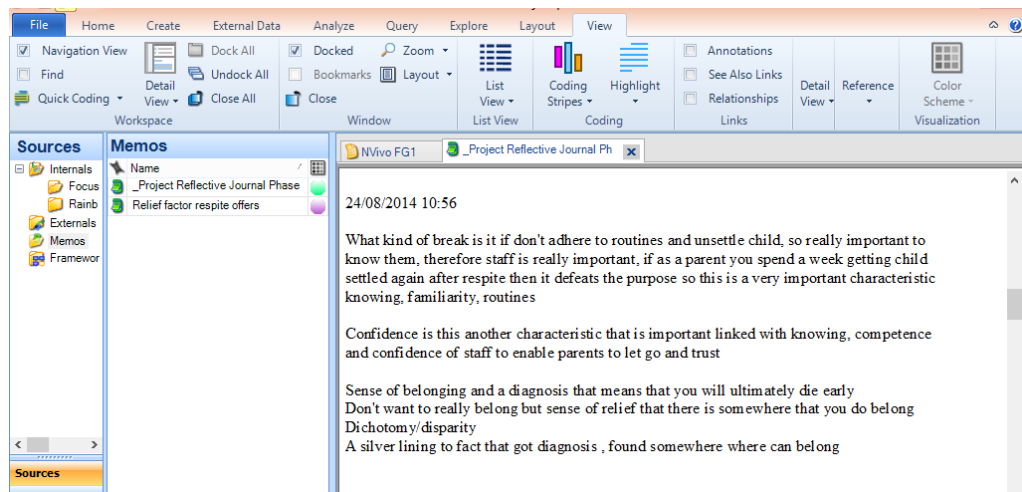


Figure 3.5 Snapshot of copy of a memo made in project journal

On reflection initial coding was not easy, it was a daunting prospect to face the enormity of the data that had been collected and there were many times when I felt overwhelmed. Initially the first stage of coding felt awkward. I also grossly underestimated the time it took to code text, revisit the original transcripts back and forth, and code again. Following the coding in NVivo of the first two transcripts from the focus groups I realised very quickly that I was trying too hard to code everything. I was mechanically trying to describe everything and forcing the data to fit codes, rather than as Charmaz (2014) suggests exploring the text intuitively and allowing the codes to fit the data. Due to the flexibility of grounded theory coding there is the option to return to the data again and again, re-code it afresh, review and re-name codes if necessary. After stepping back for a few days from the data I decided to re-engage with the data using the typed transcripts. Table 3.6 is the same extract from NVivo (Figure 3.4) taken from the first focus group which demonstrates an example of the line by line coding which took place and the reflexive comments which were made alongside the coding.

Table 3.6 Example of initial coding from focus group 1

Interview transcript, Focus Group 1, Ria , child aged 11 yrs., Act category 2	Codes and In-vivo codes	Researcher Memos
My first overnight stay, weekend respite stay, was actually quite recently . It was only just this year, but the first day, we were really quite happy to embrace it , it felt like a really nice environment , it felt almost like, like my son was a majority, rather than a minority , and everything is just keyed up , and because that embracing was there, I felt confident and he felt like, this is where I'm meant to be . I know ultimately it's not , and who wants a diagnosis that means you get invited to come here? nobody wants that , but he kind of embraced it , because he was like, well there's all these people here, there's all this here , which is here to help me rather than hinder me , he kind of, really, he talked about, and in fact, after the first day, the Monday morning afterwards, he cried, because he missed all the people that looked after him, (laughter) in the right way , he was like, they don't mind doing everything that I need them to do and he's in charge , and things like that, and he's not getting that anywhere else , so the fact that is there, (emphasizes is) was like the silver lining , but ultimately you are there for a reason .	Recent experience Accepting off hospice , "Nice environment" Child was a "Majority rather than minority" Suitability of environment Feeling confident "Where I'm meant to be" Reality is different "diagnosis that means you get invited to come here" Embracing being at hospice Being cared for in a helping culture Sad to leave respite The right way to care Copying parent Control Lack of choice of services Silver lining to being at hospice "there for a reason"	Environment enables accepting? How? Parents need to feel belonging, are they searching for this? Nurturing and helping culture Diagnosis dictates entrance to hospice, Not there by choice, is this similar for all parents? Characteristics of what is important relationships, Control, same as home – parents need to feel still in control? parental responsibility Lack of choice of services Real reason for being at hospice, what is this?

3.5.2.3 Focused coding

The second stage of analysis occurred concurrently whilst continuing to collect new data from subsequent focus groups. At this stage of analysis the researcher begins to look for relationships and patterns in the data by sifting through the list of initial codes, comparing codes to each other and determining which ones relate to each other and therefore could be grouped into a smaller number of focused codes. Charmaz (2014:141) suggests asking questions like: 'In what ways do initial codes reveal patterns?'; 'Which codes best account for the data? and 'What do comparisons between codes indicate?'.

NVivo allows the researcher to view the data in each node at any time. As links are established between nodes within NVivo there is then the capacity to rearrange nodes, rename nodes, aggregate and merge nodes, and begin the process of clustering nodes together into a hierarchical tree (referred to as parent nodes). Any parent node can have a number of descendent nodes (referred to as child nodes). For example, from focus group 1 the two in-vivo codes 'where I'm meant to be' and 'majority rather than minority' were moved to the parent node of 'sense of belonging'. Parent nodes represent the focused codes which begin to emerge from the iterative process of reading, returning to the typed transcripts and reflecting on the initial codes.

As focused coding continued codes were examined for similarities and differences as they were clustered together. At this stage although NVivo had worked well in managing, organising and sorting the data the researcher's preference was to visually represent some of the conceptual thinking that was emerging but NVivo continued to be used to retrieve quotes from the interview transcripts. Using diagrams to map initial thoughts following each focus group helped the researcher to visually see and begin to think conceptually about what concepts were being generated from the data. Figure 3.6 is an example of the early mapping of initial thoughts from the focused coding following the first focus group. Each box shows a focused code (red bold heading) which seems to encapsulate the ideas being expressed. The writing in red italics reflects examples of the researcher's early conceptual thinking related to the codes.

Charmaz (2014: 146) comments how it is in this stage that codes "nag" the researcher; whilst clustering focused codes into preliminary categories the process of constantly comparing codes and scrutinising the data continued, and also highlighted areas for further exploration. Analytic memos were written in order to record the relationships amongst the clustered codes and the interpretation occurring. Further analysis using the same techniques continued with all of the focus groups and the three individual interviews. Whilst adding to the data, the three individual interviews which were conducted at the end of phase 1 were also an opportunity to clarify and affirm patterns that were emerging from the analysis of phase 1. During the three interviews the researcher questioned participants specifically with the intention of adding to and illuminating the preliminary categories which had been developed.

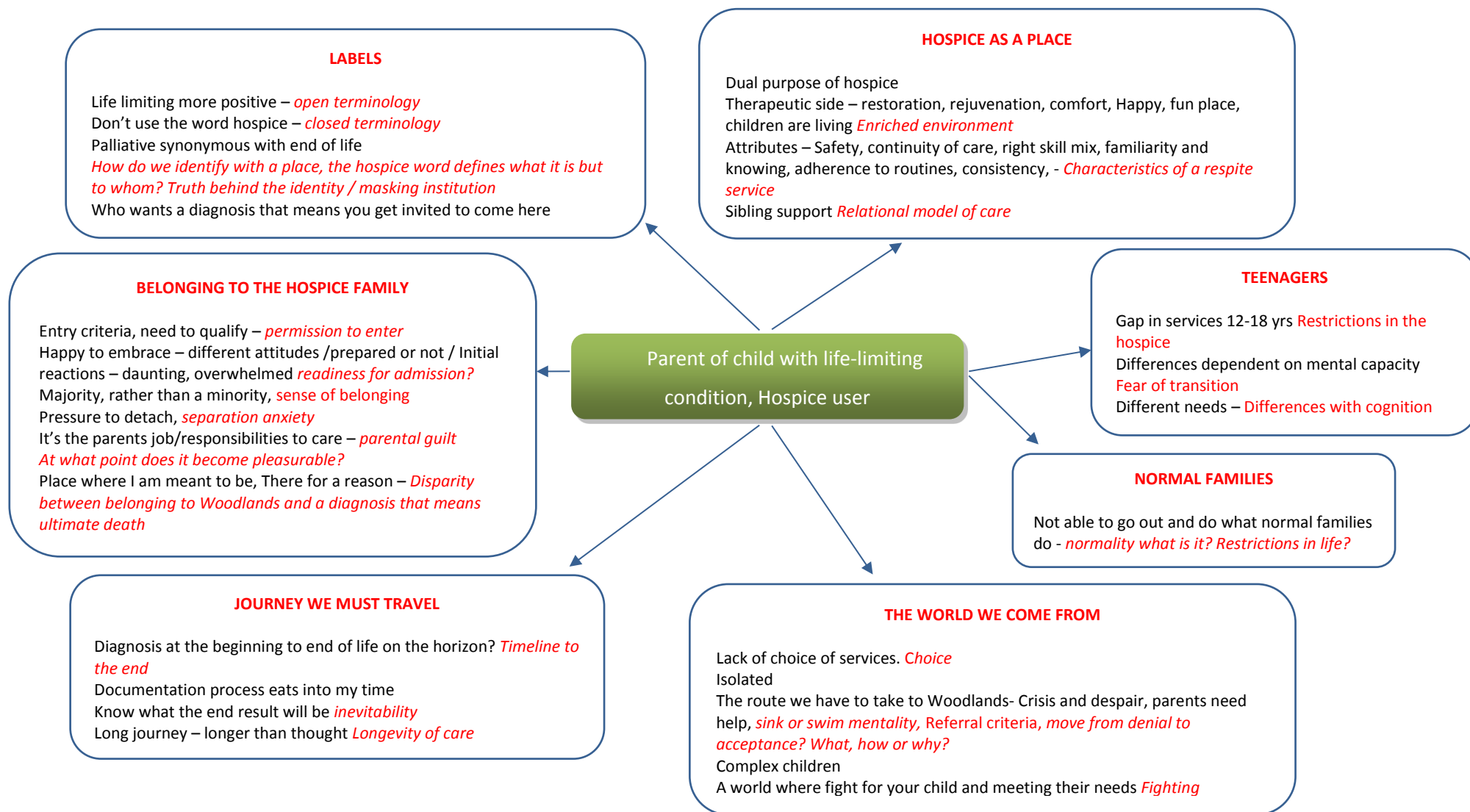


Figure 3.6 Example of early mapping of initial thoughts from focused coding of focus group 1

As this process continued, analytical thoughts grew in complexity and clarity and theoretical sensitivity increased as patterns were developing. Theoretical sensitivity, another fundamental component of grounded theory, is the ability to have insight into the data and from this make something out of the data. Charmaz (2014:161) defines it as the ability to understand and define phenomena in abstract terms and to demonstrate abstract relationships between them. The process of memoing was fundamental at this stage and as conceptual ideas emerged more memos were written. The memo below is an example of the conceptual thoughts that were emerging related to the sense of journeying undertaken by parents with their child; whilst at the same time searching for some normality in their lives.

"They are on a journey with an inevitable end, its stormy and presents many challenges along the way. They enter into different worlds, back and forth, like a road map, get a little lost along the way at times, searching for sense of relief, then find something many of them forced to find, one way street, to Woodlands which offers a little normality for a time. They snatch a glimpse of what normality would have looked like for them, or do they, most of them so tired they don't get to do all the things they want to when they get some respite. Interesting how many of them identify themselves as not leading normal lives? What is normal? They describe a role where their identity as a parent is lost, they are a carer, an employer, a negotiator, not a mum or dad. They become an expert in something that they didn't choose for themselves, life dealt them that hand. But it's not forever, as child grows and adulthood looms they have to leave that safe place and start venturing to another world which they fight against even more than they did to get to Woodlands".

At this stage it was also important to make sure that the ideas that emerged were inductive, as before with the process of constantly comparing codes and focused codes, constant comparative analysis was concerned with comparing preliminary categories with each other and looking at the inter-relationships between each category. Table 3.7 is an example of some of the preliminary categories developed from the overall analysis of the data set from phase 1.

Table 3.7 Example of the development of categories from analysis of phase 1

Focused coding	Preliminary Categories
Qualifying for entry Inevitability of end of life Complexity of children's diagnoses In crisis Anxiety of separation Struggle with denial and guilt Parental responsibility Acceptance Ready for admission Lack of choice of services Searching for something	Entry criteria Parental struggles Ready for admission Lack of choice
The hospice family Family centred care Sense of Belonging Belonging that means you will die Identity associated with hospice Familiarity and knowing Safety and security Continuity and consistency Attention to detail Relational model of care Flexible service delivery Enriched environment	Belonging to hospice Juxtaposition of belonging Attributes required for belonging

As analysis progressed it became apparent that there were many ideas and questions from the data that warranted further exploration in phase 2 of the study. For example, from the category 'ready for admission' the researcher wanted to explore with the non-hospice user group: What defined readiness for respite? What was the difference with non-hospice users? Were experiences the same for other respite services? What was the perception of criteria for entry at a hospice? and, What were the barriers to entry? It also was apparent from the analysis that there were two separate groups of children at the hospice with different needs, those who were cognitively impaired with complex needs and those who were cognitively able with primarily physical disabilities.

The analysis of phase 2 data was conducted using the same process described above following each interview. When it became apparent that there were two separate groups of participants; the hospice aware group and the non-hospice group, these were initially

treated as separate data sets. The constant comparative method of analysis meant that the data were continually interrogated. Initial ideas were challenged and words used to label preliminary categories were refined to improve their 'fit' with the coded data it represented and capture the meaning more accurately.

3.5.2.4 Theoretical coding and integration of the three data sets

In the final stage of analysis, the process of theoretical coding was used to begin to theorise the preliminary categories which were emerging from the three data sets. Whilst the process of theoretical and conceptual thinking began when analysing the first data set (hospice users) it was not until completion of analysis of all three datasets that more abstract concepts emerged. Using different colours to identify the three separate data sets of hospice user (HU), non-hospice user (N-HU) and hospice aware (HA) the tentative categories were reviewed alongside the analytic memo and compared across all three data sets for similarities and differences. On reflection this was the most difficult stage in the analysis process as the leap in critical thinking and imagination was challenging and was dependent on the judgement and insights of the researcher. Table 3.8 is an example of the preliminary categories which were identified from each data set that appeared to share meaning with each other.

Table 3.8 Example of the preliminary categories across three data sets which shared meaning.

Preliminary categories (HU)	Preliminary categories (N-HU)	Preliminary categories (HA)
Lack of choice of services	Separation anxieties	Geographical difficulties
Parental struggles	Right place for respite	Separation anxiety
Entry Criteria	Right time for respite	Maintaining Family
Ready for admission	Difficulty in decision making	Lack of services
	Inequity of provision	Changing social circumstances
		Parental responsibility and guilt

Further analysis of the above example led to the development of three theoretical categories which identified the abstract concepts of the idea that parents had to be ready for respite- '*in readiness for respite*'; the idea that in order to be ready there were many barriers that had to be overcome – '*internal battles*'; and the idea that accessing respite was not easy or clear – '*rite of passage*'. As the process of theoretical coding continued across the three data sets it was evident that the category labelled as 'maintaining life' did not conceptually fit, it seemed to fit better with another idea of '*doing life*'.

The flexibility of grounded theory analysis means that emerging thoughts, categories and themes can be continually reviewed, refined and clarified. In the above example '*rite of passage*' did not appear to accurately reflect the idea that choice was so limited that the hospice appeared the only option for these parents. Subsequently the category label was reworded to '*hospice the only option?*' The final stage in the integration of the data sets was to find a form of words which would adequately reflect the content of the core category, in the above example, '*crossing the threshold*' encapsulated the ideas that parents were '*in readiness for respite*' by overcoming many challenges and '*internal battles*' to find that they did not have much choice in terms of what was available for respite, '*hospice the only option?*'.

Further theoretical analysis across all three databases using the same technique generated further categories and three main conceptual themes described as "Coming Home", "This is Living Now" and "Moving Forward". Figure 3.7 is a diagrammatic representation of the three themes, categories and subcategories which will form the remaining findings chapters of the thesis, an interpretive account summarising and analysing the specifics of each theme. Illustrative quotes from the parents are used by the researcher to tell their stories. Even whilst writing the findings chapters things were changing, as categories were reviewed to ensure they were as conceptually perfect as possible and accurately portrayed parent's stories. For example, '*In readiness for respite*' portrayed the sense that parents were at the point where they were fully prepared for respite, but following further consideration the wording of the category developed to: '*ready for respite*', the verb portrayed the action and the idea that this was something that parents were getting ready to do. Appendix 11 demonstrates the continual process of refining theoretical categories to ensure the data was conceptually fit.

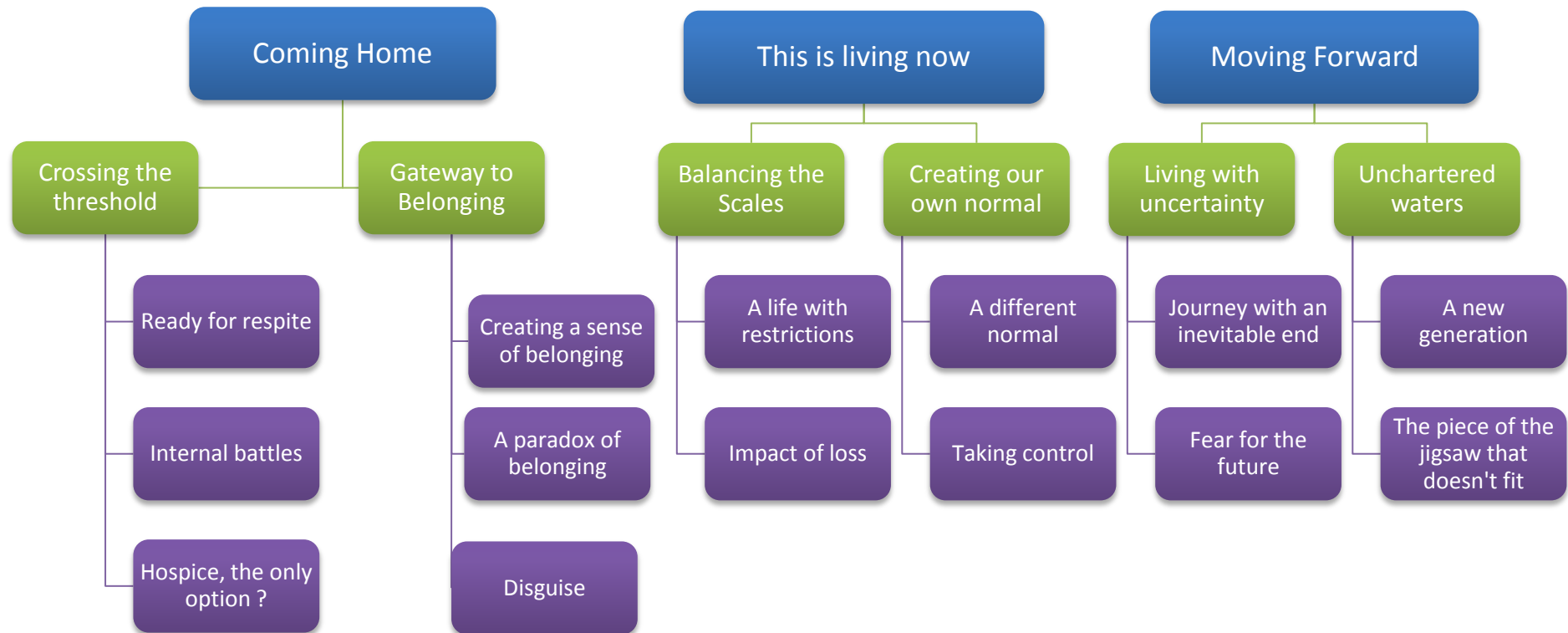


Figure 3.7 Three themes, associated core categories and sub-categories identified following analysis of data.

3.6 Conclusions

This chapter has examined in detail the methodology underpinning the study, the design and conduct of the study and the process of data analysis. In chapters 4, 5 and 6 the categories and subcategories identified from the analysis of the data will be presented in the three named themes described as “Coming Home”, “This is Living Now” and “Moving Forward”. Following this, in chapter 7 the themes and concepts developed from the grounded theory analysis of the findings, will be explored in the context of the literature. A discussion pertaining to the theory developed will be presented.

Chapter 4 Findings: Coming 'Home'

In this chapter a detailed account of the results of the systematic thematic analysis of the data will be presented in the form of categories and sub-categories related to the first theme Coming 'Home'. Two core categories were identified 'Crossing the Threshold' and 'Gateway to Belonging'. Each of these categories and their associated sub-categories will be discussed. Figure 4.1 illustrates the categories and sub-categories for this theme Coming 'Home'.

In this chapter the idea of coming 'home' depicts the desire, the sense of searching that parents have in seeking out a place, other than their actual home, where their child can access a caring environment and the parent/s receive some respite from caring. Coming to terms with the need for respite was a huge struggle for many parents and certain characteristics which need to be in place before parents will really accept the respite have been identified. The idea of coming 'home' also reflects the sense of relief experienced by parents, when they finally find a place which creates a sense of home for them, a place where they feel they belong, they know their child will experience what is familiar, as Shona explained:

"whether we like it or not we will always, we will never accept anyone is as good as us to look after our little ones. So it's having the comfort that they [carers at the hospice] are almost there" (Shona, HU).

The unexpectedness that a sense of belonging is generated at the hospice and that parents feel they have come 'home' lies in the ability of the hospice to disguise its true identity. The reality is that a paradox exists in which the hospice, a place commonly thought of as a place for dying, becomes a place for living.

4.1 Crossing the Threshold

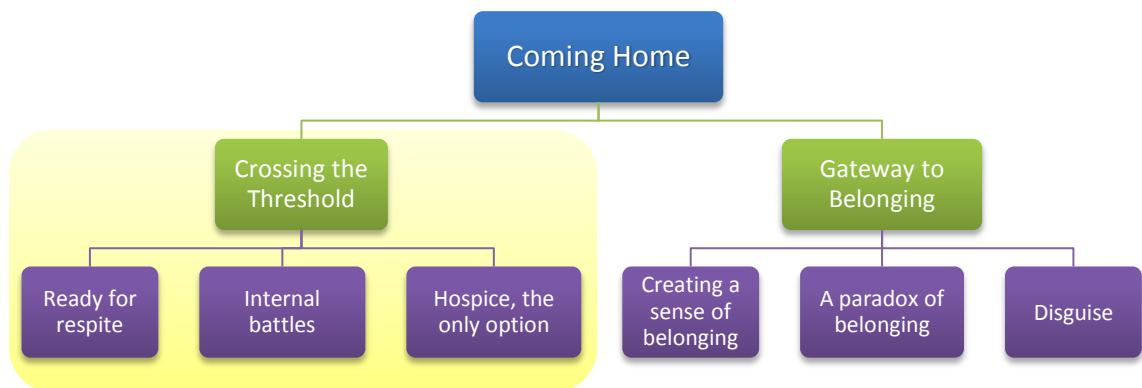


Figure 4.1 Theme One - Coming 'Home': Core category - Crossing the Threshold

Before parents were 'ready for respite' they first had to move from a stage of coping by themselves to accepting the need for help, and parents described the external and internal factors which influenced their decision making. External factors which parents described were a lack of available support, the needs of other family members other than the child, timing of referral, crisis situations, acceptance of terminology used to describe conditions and finally the use of the hospice for respite services. 'Internal battles' such as those reflected in the words of Felicity, depict the internal feelings and emotions that parents struggled to overcome in order to accept help:

"I couldn't get my head around the fact that it seems acceptable to leave a three, four year old, just drop them off somewhere, I wouldn't have done that with my others, so I don't know why it would be acceptable to do it with Maddie, I don't feel comfortable dropping Maddie off and then coming home. That's alien to me, absolutely alien. But that's not to say that I don't want to sleep all night" (Felicity, HA).

It was the overriding need for rest which resulted in many parents ultimately deciding to cross the threshold and accept respite help. However, they then found the choice of respite services was limited. Amy's words reflect the continued search by many families for help:

"I was trying to find support, because I was all on my own, and I rung Epilepsy Line, but there was all various forms of epilepsy, and he didn't fit into that category, and I didn't know, I used to exhaust myself looking for help" (Amy, HU).

Ultimately the only source of respite help for many families was to access the hospice.

4.1.1 Ready for respite

It was clear that before parents would consider any form of respite they had to believe that the 'time was right'. There was no clear consensus across the three groups (HU, HA, N-HU) as to when that point in time occurred; some parents described coming to a point of recognition and acceptance of the need for help quickly whilst others, particularly within the non-hospice user group, were still not at that stage. Caitlin (N-HU) explained, *"I don't know if I can do it yet, but I keep thinking maybe in time I'm going to need that break"*. The decision to use respite services or not was a balancing act between coping and not coping and accepting a need for help. Ruth's words reflected the difficulty in deciding which route to choose:

".....so it's kind of a fine line isn't it, because in a way, by either not saying anything, people like me will just plough on, and cope, but actually you do need the help, but I'm not very good at admitting that I need the help" (Ruth, HA).

Fran (HA) was like many parents who were in a situation where *"nobody else could look after their child"*. Although parents acknowledged social networks of friends many of them described situations where friends had *"moved on"* and they felt *"left behind"* and *"isolated"*. Others stated that the complexity of caring for a child with a life-limiting condition meant that friends were more reluctant to help out, because they felt inadequately trained or prepared. Fran commented on this sense of being on her own:

"Normal kids you can leave with a friend for an hour, or, you know, somebody will come and stay in your house for an hour while you go and do something, but you can't with these children, you can't leave them anywhere, and we were just desperate" (Fran, HU).

For many of the parents the decision to accept help was influenced by the needs of people other than the child for example, the fact they had other children's needs to consider. For four of the mothers, being a sole parent meant admitting that they *"needed some rest"*. For others the need to have time with their partner influenced their decision making:

"It's just being able to actually go out, and me and my partner can actually go out for a meal one day maybe, on our own, in a restaurant, wow!, [lots giggles]"

so yeah, there's just nobody else. There's no family, there was no friends, nobody to help us out, so" (Laura, HU).

For some parents like Pauline, the fear of not being there for her child in the future caused her to prepare for all eventualities:

"....and also that's another reason why we needed to have a look at this respite. Because if anything happened to me, or [name of husband], who would look after him?" (Pauline, N-HU).

For many of the parents it was a feeling of desperation which led them to seek help. John (HU) described how they as a family *"were in a bit of a mess"* when they sought help. Others concurred with this and described *"torrid times"* (Amy, HU). Josie's (HA) words depicted her desperation and recognition that she needed help, *"we were just at the point, you know what, something's got to happen. We need to have some help"*. Parents felt that accepting respite was perhaps a route that they had to take. For some families the decision to accept respite was brought about by a crisis. Ruth (HA) and Mark (HU), like several other parents described situations where, despite admitting they preferred to cope on their own, a crisis arose which resulted in referrals for respite being made by concerned health professionals:

"Martha has challenging behaviour at times as well, and I think there had been a particularly bad week where she basically managed, we both ended up on the pavement, you know, I was sort of on the floor, because she'd managed to get me in a, used to pull hair quite badly at the time, and we'd end up in a situation, trying to get in the car, and she sort of got me, where I was actually struggling to hold her and be safe, whatever, and we both ended up on the pavement, and she was kind of going for me, and there had been a whole week of events like that, I had an appointment in the clinic on the Friday, and somebody said 'How are you?' and that was it 'Wwoahhh' Flood gates opened" (Ruth, HA).

Mark talked of the tiredness that he and his wife both felt that led them both to accept help for their son:

"We were referred by a consultant at [place name], when we went through a torrid time, with very complex behaviour, and erm, it was really for our benefit, rather than my son's, because we were just exhausted" (Mark, HU).

Amy (HU) described her circumstances where a referral was made to the hospice following the admission of her son to intensive care. At that time his outlook was poor and

the referral was initially for end of life care. However, as his condition improved what was initially an end of life referral became a respite break. Amy explained:

"It was a bit of a torrid time, I would imagine, we were in ICU at [name of hospital], and I think the team thought that we need to be, looking at going to Woodlands, because of his illnesses, but he was okay in the end – so we kind of went that way through the door because of what was happening to him, I suppose they thought we needed to be there" (Amy, HU).

Both Mark and Amy described the situation that they were in at the time as *"torrid"*, reflecting a situation where both parents were at a point where life for them was so difficult they recognised the value of help and a break from caring for their child. The value of focus group interaction is that participants are able to 'explore connections' and to reflect on their experiences (Waterton and Wynne, 1999:132). In this case Mark (HU), in the same focus group as Amy, echoed her words to describe how he and his wife were also going through a *"torrid time"*.

For other families, rather than their own particular circumstances, it was words and medical terms used by health care professionals that had an effect on decision making. The use of medical terms, such as 'life-threatening' or 'life-limiting', to describe the complex needs of their children was difficult for some parents to accept. Ria (HU) described how she was not *"ready to hear the life-limiting thing"* and therefore did not accept help when it was initially offered. For Shona, words used at the right time affected her decision:

"I don't think it could have happened any earlier, we weren't ready to hear the life-limiting thing before we did, I don't think, and when it came, we were surprised at how . . . accepting we were of that really" (Shona, HU).

Both Shona (HU) and Sharon (HU) described how the word hospice could also create a barrier for parents; Shona said, *"it's kind of an admission of what's going to come"* and Sharon explained *"it's a closed door, and it's because of that terminology"*. Linda described the hospice as a *"hurdle"* because of the associations of the word hospice with death:

"I know having spoken to other parents with children, that that's the last place that they would go, and it's really hard to get over that hurdle that, that might be a place to die" (Linda, HU).

One parent from the hospice aware group questioned whether the hospice should actually be used as a place of respite, *"so, is it normal, or right, is normal the right word, to send your*

child to a hospice and all that entails?" (Felicity, HA). For Penny, despite reaching a point of accepting help, the physical process of entering the hospice remained a challenge and she described her journey of negotiation and how it was another parent who convinced her to finally look at the hospice:

"It took me three attempts to get here. I even drove up to the gates, and I said, 'No, not for me'. Somebody mentioned to me that Tanya was a good candidate for Woodlands, and I said 'I thought you only went there when you were really ill'. Obviously Tanya is quite ill, terminal, well they are all life-limiting, and I said, 'Oh no, it's only for children that are really ill'. And they said 'Well is she ever going to get better?' I think you're always in denial of your children, whether they are well or poorly, so, my friend came, her daughter comes here, and she said, 'Oh it's lovely', and she was telling me all about it, and I said, 'Well, if that's alright for you', but anyway I came, and I came on my own, my husband wouldn't come for quite a while after. Erm, but then I, it's like me, you have to come when you're ready don't you really?" (Penny, HU).

Being ready to accept the need to access the hospice was influenced by external factors described above; lack of available support, the needs of other family members other than the child, timing of referral, crisis situations, acceptance of terminology used to describe conditions and the use of the hospice for respite services. Closely linked to external factors were the 'internal battles' that many parents reported as they tried to come to terms with the condition of their child and the decisions that they were making.

4.1.2 Internal battles

Within society the role of a parent centres on the ability and responsibility to nurture and raise their child/ren. There was a strong sense that coming to terms with the need for respite and ultimately being able to accept help for many parents was influenced by many internal emotions and feelings. Pauline's words reflected the abnormality of asking someone outside of family and friends to look after your child:

"I think most parents are trying to do as much as they can for the kids, from day one, that's the goal but the goals are changing: giving someone else that, you know, giving it over to someone else is not normal" (Pauline, N-HU).

Bernie clearly demonstrated the conflict that parents' experience in terms of their parental responsibilities:

"I can see 99% of parents become parents and that's it, they, your, that child is your responsibility, so any help that you get you always feel guilty because you've give birth to that child. That's your responsibility. So, so, it's difficult" (Bernie, N-HU).

In addition to responsibility, it was Jane's (HU) words that reflected the sense that accepting respite would mean surrendering her parent role, *"it's hard for someone else to take over and do your job."* For other parents the perception of relinquishing some of the jobs integral to the role of a parent, even for a short time in a respite capacity, meant that they were consumed with guilt and feelings of loss. John described the way in which his wife's anxiety manifested itself:

"I don't think she has been for ages to drop him off, she doesn't like dropping him, because she still feels that you know, it's her responsibility" (John, HU).

Parents discussed the varying strategies they used in order to cope with the feelings of guilt, loss and conflict defined above. Mona (HU) described how when she left the hospice she *"goes blind and deaf,"* suggesting that to cope with the separation and anxiety of leaving him she made an active decision not to think about her son. Pauline (N-HU) described how the only way she could rationalise the separation from her son was by pretending he was going to grandparents for the night, *"I've just got to think that he's going to Mama and Grandad's"*. Despite this rationalisation she talked of her emotional turmoil if she thought too much about him whilst he was away:

"Well, I try and organise to do something that I couldn't have done while he was, you know, and once, where I hadn't organised something, and I just cried, because I just missed him so much. So I've got to keep my mind occupied not just sit thinking about it" (Pauline, N-HU).

The idea of it being more normal to leave your child with a relative was something that other parents spoke about, but the complexity of caring meant that this was not possible for many of the parents:

".....because you normally leave your granny in charge of any baby that you have, granny would love that, but granny can't tube feed. Granny can't deal with a child that can't hold her head up, or you know, is constantly sick, because it's not within their sphere of things" (Fran, HU).

Across all three groups of parents a recurrent sense of anxiety was associated with being separated from their child. For Edna the suggestion of someone else looking after her child created a strong sense of alarm:

"....because we were awarded 24 overnights. And at the start that was really scary. Because obviously we had cared for him 24/7 from birth, and it had been very intense, and whatever, so, so it was like, 'Oh my god, they are going to take my baby off me.' " (Edna, N-HU).

Although described primarily by mothers, this sense of separation anxiety was not limited only to them. Pauline described how her husband struggled with the idea of their son, Fred, going to an alternative respite location other than home, she said:

"He's still not, really, okay with it, when we took him, and then me and [carer] sat down planning the next, he wasn't happy. Because he doesn't like it, he's still having to go, still definitely struggling with that. Feeling guilty that his son is going off somewhere. I know, I do, too" (Pauline, N-HU).

Accepting help and agreeing to finally cross the threshold was not an admission that leaving their child was going to be an easy task. When referring to the staff at the hospice, despite acknowledging their good intentions, Jane (HU) expressed her frustrations at being asked too quickly to leave her child, *"but like they really encouraged you to leave them, so they can give you a break, but you're not ready to, you know, leave them"*. Ann's words (HU) reflected the same sense of being rushed, *"sometimes some of the staff put too much pressure on you to try to start detaching from your child."* Whilst respite care may offer a physical break for parents in some cases it did not appear to offer an emotional break. Jane (HU) who despite using the hospice described her emotional turmoil, *"It's not a break, it is torturous for me"*. Bernie, who used an alternative respite facility which was not a hospice described feeling bereft when leaving her son for the first time:

"I just felt like erm somebody had [pause, upset]..... robbed me, and taken everything away. You feel as though you're not capable of looking after them" (Bernie, N-HU).

The internal battle to accept help continued even when the child was being cared for in their own home. Abi described her internal battle to accept carers within the home:

"I like to get up in a morning, and, get stuck in, this is my fight with myself as well. I've always been independent, I've always done everything myself, never asked for help. Just got on with things, and obviously I had to start having help, and it gets more and more, and part of me don't want it, but part of me knows, actually you need it. You know, so I then have this fight with myself, which mentally exhausts me as well" (Abi, HA).

While parents struggle with the concept of accepting respite help and dealing with the emotional battles described above, the ability to finally cross the threshold was reflected in the choices of respite available to families.

4.1.3 Hospice, the only option

Across the region there was clearly a lack of choice of respite services and facilities available to families. This created strong emotions in some parents; in one focus group there was profound agreement as Jane vehemently described the lack of services available:

"They are shutting everything down,..... there's nothing in place for, well for all spectrums really, but especially severe complex children, because of their health and nursing needs, you're just stuffed !" (Jane, HU).

Bernie described her search to try to find something suitable for her son's needs:

".....379 care homes have I looked at, and only one has come out on the CQC that is suitable for him, and that is all in this area. They deal with dementia care, they deal with old people, and there is nothing for young people with complex needs. And it's terrible" (Bernie, N-HU).

As a result many parents explained that they accepted the hospice referral as their only option because as Emma (HU) explained, *"it's a life line for us parents, because where else do we get respite from?"* When asked about referral to the hospice the perception amongst parents was that entrance to the hospice was dependent on certain criteria being met. Parents from the hospice user group explained that having a child who was *"life-limited"* (Ria, HU) or *"terminally ill"* (Jane, HU) meant that you qualified for entry to the hospice. However there were a few parents who did not fully understand the criteria and, ultimately they ended up at the hospice purely because their child's diagnosis of a life-

limiting condition had resulted in a health care professional making a referral to the hospice.

There was also a feeling amongst some parents that the criteria meant that in terms of access to the hospice certain children received priority. Parents in the non-hospice user group described what they perceived as a hierarchy of seriousness of condition which affected whether they would be eligible for hospice respite. Bernie (N-HU) believed that she would not be *“able to tap into a service, like the hospice”* because her son’s complex needs were *“not enough”*. Verity (HA) commented that the hospice was *“for children with very complex needs”*. Paul (HU), whose son used the hospice commented, *“we realise our son probably isn’t as desperate as some, so it tends to be two or three times a year we use Woodlands”*.

This sense of limited resources was evident in the accounts of four parents within the hospice user group who expressed concern that increasing demand for respite services meant that the entry criteria for the hospice was becoming more stringent with the potential that their child may not be eligible for services in the future:

“But their [the hospice] criteria seems to be becoming more, where they have to have a condition where they know for definite they are not going to survive into adulthood, and also the cancer care, that wasn’t there before, where now, they seem to be opening their doors” (Jill, HU).

For some parents the realisation that respite services were limited appeared to be associated with the risk of committing to the idea and the fear of being turned down. Fran’s words reflected the unfairness of this and the unacceptability of this as a situation:

“It was done, not as a, you can have a place, it was a well apply and you might get a place, and you might not, which again is, you know, unfair, because you hear of other families who’ve applied and don’t qualify, and that’s so cruel, you know, you raise somebody’s hopes that there’s access to people who can help, who can understand about your children, to, even to, even the coffee mornings for the parents, you now, but, no you can’t come, the door’s shut against you. That’s quite unfair” (Fran, HU).

There was also a lack of information about what respite services were available and like Ruth, parents who did not use the hospice expressed a wish for clearer signposting in terms of availability of resources:

"I think one of the key things is having the knowledge of what is available. And I think over the years I've not known what's been available, and you've kind of relied on other parents maybe in conversation, and they've said "oh we do this, or we do that" (Ruth, HA).

Whilst parents also recognised the value and support received from other parents, they also suggested that, in some cases, there was the potential for gatekeeping as a protective mechanism:

"But then you do come across a parent who finds out things, who doesn't want to tell anybody else because they think they will lose their right to that service" (Josie, HA).

Geographical location also acted as either a barrier or facilitator in encouraging uptake of services. One parent commented that many of the parents accessing the hospice had to travel *"quite a distance"* but did so as they were left with little choice, as Sharon (HU) said, *"it is the only option"*. Despite the fact that the average distance from home to hospice for parents in phase 1 was 20 miles, many parents felt that the hospice was *"covering too huge an area"*, and for some parents like Caitlin, who lived 34 miles from the hospice, the perception was that it was too far away:

"The only thing that puts me off is the travelling. That's the thing that puts me off. Travelling. Because it would take, 'How far is the hospice?' It's quite a long way isn't it?" (Caitlin, N-HU).

Ultimately the overriding factor for accepting the hospice as an option for respite was the fact that the hospice offered parents the potential for much needed rest. Like many parents Katie's words reflect the positive relief that respite offered:

"....so to not be let down, to have a service that is completely, you know, what do you need, what do you want, what's the best is erm, entirely refreshing, and that's made a huge difference" (Katie, HU).

She continued to describe how she *"just got to sleep, for a whole two days"*. This idea of sustainability, a sense of renewed energy was further described by Ann (HU) who

explained how because she can “go up to bed and get a full night’s sleep instead of the normal, being up with him every hour” then she “can get up in the morning fresh as a daisy”. The benefit for her was that then she “can go out for the day because I’ve got the energy to do that compared to a normal weekend, I’m like, I can’t, I’m too tired”. Mark’s (HU) delight was evident in his words “I didn’t realise how tired I was, because I actually slept for 24 hours the first time, [laugh], yeah, wonderful”. The necessity for sleep was something that was so strong that it meant parents looked forward to their allocated respite, even suggesting that there was something hypnotic, a drawing-in influence to the hospice, as depicted in the words of Amy:

“Every time I approached Woodlands I just smile, because I just think, going to sleep, when I drop off, and we just sleep, and it’s like you’re drugged in the morning, because you sleep so well, because you know you can” (Amy, HU).

In summary, making the decision to accept respite help was not an easy one for parents as they balanced both external and internal factors to accept the need for help. Unfortunately within the geographical area of this study the choice of respite services was limited and for many families often the only choice was the hospice. However, for those families using the hospice the findings demonstrated that this was a pleasurable experience. The factors which contributed to the acceptability of the hospice and other respite facilities will be discussed in the second category of this theme described as ‘Gateway to Belonging’.

4.2 Gateway to Belonging

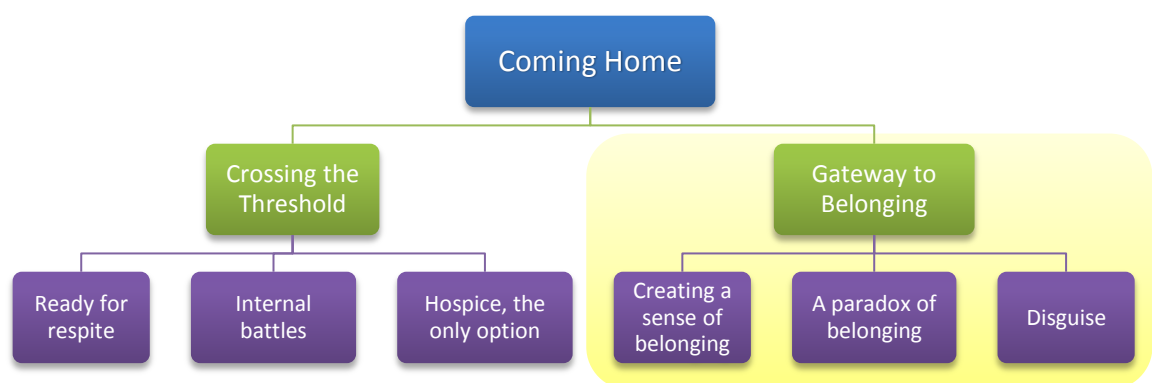


Figure 4.2 Theme One - Coming ‘Home’: Core category - Gateway to Belonging

Having made the decision to accept help parents needed to feel reassured that their decision had been the right one. 'Gateway to Belonging' describes the search by parents for the right place for their child to receive care, that encompasses the characteristics that they are looking for in creating a sense of the same experience as their place of home. In essence, the parents needed to be assured that their child would ultimately feel a sense of belonging in the place of respite chosen. These characteristics helped parents to feel they had made the right decision for their child and ultimately therefore experience some sense of freedom from the internal battles of guilt and separation previously described. Whilst there was a strong sense of agreement across all three groups of the characteristics necessary to enable parents to relax and accept respite offered, it was the group of hospice users, who having experienced this feeling of belonging at the hospice, described the relief they felt by finding somewhere their child belonged. The paradox in this was that entry to the place where they felt they belonged was because their child had a condition which meant that their life was limited. The feeling of belonging prevailed despite the recognition by parents that there was another side to the hospice; the fact it was a place for end of life care. Parents believed that this side was subtly hidden by the hospice, and as a consequence the hospice became a place where parent and child experienced respite in a happy, vibrant environment where they felt they belonged.

4.2.1 Creating a sense of belonging

Parents across all three groups reported that there were certain characteristics for any respite situation, which were fundamental in creating a sense of belonging for parents, in providing reassurances of choices made and of a service where they trusted that their child would be well looked after. These characteristics were closely linked, complimenting each other, working together to foster a feeling for parents that their child belonged in the respite situation.

Whilst many parents recognised that *"that no one else can look after their child as well as they can"* and that in an ideal world the safest place to receive care was in their own home, parents consistently stressed the importance of safety and security as a characteristic required for respite outside the home to be acceptable. Many parents talked of safety, for example knowing *"he's safe"* (Stuart, HU), or *"I know he feels safe and secure there"* (Katie, HU). The reassurance of safety and security offered some relief to the parents, for example when referring to her daughter Charlie (HU) described how the hospice was a place that

she felt was *"totally safe to leave her"*. However, it was not only the parents who needed to feel safe and secure. Shona (HU) described these aspects were also important to her son, *"It is trust and safety. They are the two he talks about"*.

For children and their families there was safety and security in the familiar and, for some, this was linked with the environment. Caitlin describes how she believed her son was:

"...happier in his own surroundings with his own things that he's got. When he sees his own equipment and things, he just, oh, he knows where he is, whereas he goes out, you can see he's thinking, 'Well, where am I? What am I doing?' " (Caitlin, N-HU).

For others, safety and security in the familiar environment was related to the relationships formed between staff/carers and the child and family. The sense of the need for children to be kept safe and secure by the staff that were caring for them was heightened when children were unwell, Edna (N-HU) summarised these thoughts, *"it's knowing what to do in that situation, and obviously only somebody, probably somebody that's worked with him for a while would understand that"*. Parents across all three groups highlighted the need for carers who knew the child, independent of the type of respite experienced. Several parents emphasised that for many children with life-limiting conditions they were *"relying on others to think for them"*. The sense of total dependence of the child heightened the anxiety many parents faced with inconsistency in carers. Bernie (N-HU) described how at home, *"sometimes the young people are really frightened of the people that come in"*. Abi, whose son has respite carers at home, described how frustrating it can be for children and young people:

"It's always about consistency. That is the one thing what makes life easier, when you've got the consistency of the same carers. Because not only does Simon have to explain all the time, so do I, and you just get so fed up of it, you know" (Abi, HA).

For parents consistency also meant that carers understood the intricacies of knowing their child and their child/s routines. Ruth talked of the need for carers to know what was normal for a child so as to recognise the abnormal, when she said:

"I suppose there's an element of me that's apprehensive, because she is new to them, they don't know her particularly well, and recognising those signs that indicate she might not be feeling very well" (Ruth, HA).

For parents, children and young people it is *"the routine of doing things the way you do them"* (Abi, HA). Abi continued to emphasise the importance of staff knowing her child when she hinted at the frustrations that her son felt, *"he says the staff don't know what they are doing and he's got to keep explaining, which gets on his nerves..... whereas if you know him, you know what to do with him"* (Abi, HA).

This sense of knowing and understanding their child's routines continued with Larai who described the method she and her husband used to fit the overnight ventilation mask on their daughter:

"We have a knack of putting on CPAP every night, whereas a normal place, would probably think oh it's bedtime and she's awake, put the CPAP on, sometimes in hospital they strap it to her face, and it marks her face, but literally David lets her fall asleep for an hour, and then, when she's half asleep, puts her on it" (Larai, N-HU).

A minority of parents described their frustrations when routines were not followed. Suze (HU) described how, *"if he comes out of that routine, when he comes home, to go back to school, it takes a week to get him back"*. Caitlin's words reflected her view that familiarity and routine could only be achieved at home and in her case meant that she would not consider using respite services outside of the home:

"Because I have never ever been out of this house, with Peter, and had the equipment that I've got here, and felt like everything run smoothly. Every holiday we go on, everywhere we go, it is just, hard work, for everybody.And he loves to get in his own wheelchair, and he knows the street, and he knows where he's going, and he knows which car he's going to get in, and it's just routine really, and he seems to like that, and, I don't know, I just worry that if he goes to stay somewhere else, that I'm not there to keep an eye, I don't know, it's just, probably me, you know" (Caitlin, N-HU).

Consistency of carers was one characteristic that many parents felt was not being met in the respite services they were receiving and therefore detracted from the sense of belonging that they were seeking. Within the hospice environment parents struggled to understand why children were cared for by different staff on a daily basis. The sense of frustration experienced by parents was summed up by Laura who explained:

"Continuity of care does seem a bit iffy sometimes, you can have somebody on a long day, and then somebody will come on a late and take over, rather than have

the same person, or do a one day, and do the Saturday and Sunday, but they have, the same person on the Saturday is on the Sunday, but they have somebody different on the Sunday, to me that doesn't make a bit of sense" (Laura, HU).

Many hospice user parents stated that as the hospice had grown and become much bigger, some of the personal side of the hospice had been lost. Many of them described the *"sea of new faces"* that they were met with at each new hospice respite visit. Jane explained how the lack of consistency affected her daughter:

"There's a big staff change over, so who has her in the day doesn't have her the next day, so it causes quite a lot of problems, she gets very insecure, it just upsets her" (Jane, HU).

For parents the reality of a carer knowing a child and *"knowing them that well to know their little cues and signs and things"* (Caitlin, N-HU) and to understand their nuances was dependent on carers getting to know a child and building a relationship with them. The parents explained that this could only be achieved through carers consistently spending time with the child. Ruth's words stress how building good relationships with carers created a culture of confidence for parents:

"People are really important aren't they, and having confidence in those that are either looking after your child, or whatever it is, and actually liking them as well" (Ruth, HA).

Amy (HU) described the *"comfort"* and reassurances of *"knowing that there's a good team around you that know your family."* For non-hospice users like Larai (N-HU), the idea of using respite facilities outside home meant that they first *"would probably have to go and get to know the people"*. Felicity's (HA) words concur with the importance of parents engaging with carers, *"you've just got to get that, continuity, and I suppose, us building relationships with the people that are caring for our children"*. As relationships are strengthened trust is built. Larai and David (N-HU) explained how they experienced trust when their daughter was admitted to hospital because, *"we feel that trust there, because we know them so well"*. Ria (HU) emphasised how important it is that *"a bond is created"* between child, parents and carers. The ability of parents to trust carers was also dependent on whether parents believed staff were competent and knowledgeable to care for their child. Like many parents, Banu expressed how difficult it was for parents to trust and have confidence in other people caring for their child:

"...you become so protective and who looks after the child better than yourself? And I think the more that you build that confidence in looking after your child, which you do anyway, it is the lack of confidence, and the lack of knowledge from professionals that I have an issue with"(Banu, HU).

Whilst parents acknowledged and appreciated the need for "skill mix" in respite facilities, like the hospice, fundamentally they believed that familiarity led to knowledge and competence when caring for their children. Penny gave the impression that whilst parents recognised that staff cannot know and be competent in the diagnosis attached to every child there was an expectation that a certain level of knowledge existed:

"There's so many different syndromes, so many different things wrong with each child, you can't you can't expect everybody to know everything about every illness, can you? But, knowledge, some people have to know something" (Penny, HU).

Andrew, a non-hospice user, said that he would expect that carers looking after his son would have "experience, and some knowledge and understanding of what his [son's] condition is" and his wife Edna added "look after him the same way that I would". It was, however, James who was the most explicit in suggesting that the standard that parents were seeking in staff was akin to those as expert parents:

"I think I could speak for everybody that has a disabled child, and say that nobody looks after your child, [as well as you], nobody, and that is always a concern. Are the people there that are looking after my child competent, efficient and qualified to do it? And if they're not, we don't want them doing it" (James, HU).

The final area that parents perceived as fundamental in creating a sense of belonging was the reassurance that the actual place of respite was right. Felicity's words reflected the value associated with place:

"Finding the right space, for that child, because every child is different, but when a child has complex needs and they can't necessarily tell you what's going on, you need to be able to, it's like handing somebody your new-born baby, but for every day of their lives" (Felicity, HA).

As highlighted earlier, the perception for many parents was that home was the safest place for their child to be. Verity, who had two previous experiences of using a hospice in a

neighbouring location and now had a palliative care community team offering respite at home summarised the thoughts and wishes of many parents:

"They come to us, so Jess is in her home, so much as you know, we would probably love Woodlands, home is where Jess is used to, and home is where there's all of her toys, and she loves nothing better than going for a walk and looking up at the trees and the clouds, so those sort of things, the palliative team coming here, into Jess' environment makes a massive difference, massive" (Verity, HA).

These words demonstrate that any environment where the child was to receive respite outside the home needed to have a feeling of being "homely", and arguably therefore similarities that they each associated with home as a place. Edna (N-HU) expands this further and says, *"the environment has got to be right"* and she described the presence of an innate sense which meant that parents were confident in knowing their decision was the right decision, *"it's like anything, it's like that sixth sense, it's like walking into a house and knowing you're going to buy that house"*.

Parents in the hospice user group described the culture experienced at the hospice as one where *"because that embracing was there, I felt confident and he felt like, this is where I'm meant to be"* (Ria, HU). The feeling that anxieties were reduced at the hospice was apparent in the words of parents like, Shona and Amy. Shona (HU) described a *"comfort feeling"* of knowing that when as parents they went to bed they *"don't need to worry"* because their son was being looked after by nurses who knew what they were doing. Amy (HU) explained how she felt *"joyful and uplifted"* when she entered the hospice. The sense of relief experienced by parents continued as Mark (HU) described the hospice as a *"beautiful"* and *"magic"* place. The idea of the hospice as a place of retreat, a place of peace was apparent in Amy's description which likened the hospice to a church building where *"it was like full of pipe music"* and Mark's words depict a sense of calm, *"I just found it wonderful, it was so relaxing, peaceful, quiet"*.

However, within the non-hospice user group it was clear that parents were still searching for the right place. Parents in this group felt strongly that there was inequity across the region. Comments from Pauline (N-HU) such as *"society is not kitted out for our children"*, and from Caitlin (N-HU) *"nowhere wants our children"*, reflected the isolation that many of them felt. Pauline's (N-HU) isolation was very apparent as she continued to describe how

she believed that lack of service provision meant that children with life-limiting conditions and complex needs were being *“pushed more and more into your home, so people don’t see these all these children with disabilities”*. Whilst for many parents considering taking their child to a hospice for respite remained an alien and abnormal concept, the hospice became the right place for the majority of parents in the hospice user group and in the words of Emma (HU) it became as *“close to being home as a professional establishment can be”*. However, four parents whose sons with Duchenne Muscular Dystrophy were accessing the hospice for respite had a strong sense that perhaps the hospice was not the right place for them to receive respite care and this will be discussed in more detail in a subsequent theme, ‘Moving Forward’. But for the majority of parents who were using the hospice it became a place of respite where they surprisingly experienced a sense of belonging which perpetuated a feeling of coming ‘home’.

4.2.2 A paradox of belonging

Whilst respite at the hospice successfully created a feeling of belonging in parents, the anomaly remained that the place of respite was a hospice and this sense of belonging came with a *“diagnosis that means you will ultimately die early”*. John (HU) described this as a *“kind of an admission of what’s going to come”*. Laura (HU) posed the rhetorical question *“who wants a diagnosis that means you get invited to come here? Nobody wants that”*. As Fran (HU) pointed out, when referring to the hospice, there is no escaping the fact that *“coming to places like this sort of stamps you, indelibly with that mark that you didn’t have before, it’s real and true then”*. Consequently many parents admitted that they did not use the word hospice when discussing the place of respite that they used. One parent described how when talking to her friend about her son using the hospice for respite, *“she [the friend] burst into tears, and thought it was a really scary thing [sigh]”* (Sharon, HU). Others described how, *“we’ve noticed some of our friends sort of stand back in horror, when we say he’s going to the hospice”* (Mark, HU). Parents also associated terminology like palliative care and life-limiting as words more aligned to dying, something which many of the parents were fighting against accepting and which created in many of them an initial sense of fear. For parents the use of the term palliative care spoke of a time where they would make a decision to ‘let go’:

“.....definite down slide to you know, to the end.....the point where, I use the word dignified, where you are allowing them to slip to heaven if that’s

your religious belief, you are allowing them to slip to heaven in a dignified way"
(Ann, HU).

For others palliative care was associated with comfort and symptom control, Jill (HU) described it as: *"it's where somebody isn't going to get better, and it's how you manage them, in order to control their symptoms, keep them comfortable and have good quality of life"*. Interestingly, many parents reported the definition of life-limiting conditions in a more positive format, as something that meant the life of the child was only restricted in certain areas, *"lot of people would see life-limiting as, as a bad thing, but life-limiting, just means you can't do this, it doesn't mean you can't do that, and we will find ways to do that"* (Katie, HU).

Whilst many parents admitted *"it's really hard to get over that hurdle that that might be a place to die"*, the findings showed that for all of the parents the experience gained from entering the hospice was positive, pleasing and for many a total surprise. Woodlands was described by users as a *"place of living"*, *"a place of happiness, and it's where they make every day count"* where parents *"look forward"* to the space, a place full of *"laughter, squealing and having fun"* and a place to *"live for the moment"* and *"get the most out of life"* (Amy, Emma, Katie, HU's). In contrast, as described by parents who had experience of adult hospices, they were *"muted and quiet"* places with *"lots of people looking very miserable"* places of *"trying to enjoy the last and remembering"* and a *"place for end of life"* (Emma, Jill, Charlie, HU's). Woodlands also offered a sense of hope, a sense of being able to think about the future:

"It's support, .. respite, ... meeting other families, family support days, and just, it's just helped us as a family, it gives us time to have time with the other children, the siblings we've got,because it's all about the disabled child really, in your family, so it kind of, (pause) to catch a breath and carry on, and knowing that we've got something booked, you know, in the future, I just think, it's really nice to know that, because otherwise, it would just be, well, yeah.....[pause, upset] (Amy, HU).

Once parents accepted the need to use the hospice there was a sense of freedom and relief in finding somewhere where they experienced a feeling of belonging. This was in part due to finding like-minded people to share experiences with and to gain support, as Amy (HU) explained *"I just wanted to find a group – but they were there at the hospice, and that's*

where I first felt like I'd come home". The strength of the relief and freedom experienced continued as Amy talked about how this made her feel:

"The majority of the children at the hospice are like, like, my son, because when I, when I first got to the hospice I thought, 'Ahhhh this where I belong, there's lots of other one's like mine', because I didn't know where I belonged. I thought there must be other children like mine, I didn't know where, and erm, when we were referred to the hospice, I thought that's where all the children like mine were, and I felt so comforted" (Amy, HU).

Ria concurs with Amy's sense of comfort and explained her sense of security of knowing that many of the children in the hospice were all in the same boat:

"My son was a majority, rather than a minority,and because that embracing was there, I felt confident and he felt like, this is where I'm meant to be" (Ria, HU).

The sense of belonging created was akin to the experience of being part of a family as expressed by Shona:

"I think, it's that family, and it's being with like-minded people most of the time". to flock to who you know, or what you know or whatever, and so becoming part of the Woodland's family" (Shona, HU).

By creating a sense of family feeling the hospice offered a place where the focus was shifted from the child with the life-limiting condition to the rest of the family, *"it's got, the whole family catered for. It's not, every other service is just about Rory, but Woodlands looks after all of us"* (Shona, HU). By providing a break, parents were able to spend time with their other children, with their partner, taking part in activities that were often not suitable for a child with a life-limiting condition. Many parents described the experiences and support offered to siblings which also meant that they too felt part of the family at the hospice. Laura described how her other son has made friends with other siblings at the hospice:

"He meets other people, he's got phone numbers of people that don't live close by, but he's made good friends with, and they understand. And he is looking forward to this weekend, there is a sibling weekend this weekend, and he can't wait, you know, because he is seeing these friends that he has not seen for ages" (Laura, HU).

Following acceptance of the need for referral, parents found that the hospice met the criteria they were looking for in terms of finding a place *“where all the children like ours are”*. The hospice provided an enriched environment, in which parents were, in the main, rejuvenated and where sleep was offered. It was also a place, where despite the paradox, the essence of belonging was experienced and parents felt a sense of relief from belonging to a place where they did not want to belong to and where *“although they are about helping death happen, they are about life”* (Katie, HU). However, whilst all of this is strongly positive, parents also described their view that there was a flip side to the hospice that meant their child one day would need the hospice for a different reason.

4.2.3 Disguise

Parents believed the hospice disguised its true identity and thus created a paradox. Parents described entry to the hospice like entering *“a different world”* a world that existed because they had a child with a life-limiting condition, others described it as entering the *“special needs world”*. The notion of separate worlds and the implication that the world of a child with a life-limiting condition is different from the world around will be discussed later in a subsequent theme, (‘This is Living Now’) but the significance here was that the hospice world, as reflected in Ruth’s words suggested that the feeling of belonging that existed, happened naturally:

“...that you are trying to fit into everybody else’s world, when you’re outside of yours, whereas at Woodlands, that was just the world, you just slot into it really”
(Ruth, HA).

The hospice was a place where, for a short time parents experienced a snapshot of a world where the attention was not on the illness or disability. Charlie (HU) described it as somewhere where *“it’s more focused about the child and the family and the needs of that person, and you’re not just, ... not just a number, not, there is a person behind the, the diagnosis”*. For others the natural feeling came about because of what they were expecting from the hospice, *“I was expecting it to be like a hospital, but it was like a hotel-hospital, I was just bowled over by what it was like really”*. Again the words above reflect the surprise, the pleasantness of finding that the hospice was completely different from their preconceptions. This feeling of ‘natural’, where nothing was forced, continued when describing the care that was offered in the hospice. Emma (HU) said *“the medical care is*

there, but it's not, it's kind of, I don't know, it just happens". Julie's words comparing her hospital experiences concurs with these findings:

"...think hospital was kind of like, everybody sort of stuck in a certain place, tubes everywhere, very clinical, kind of feel, and obviously there is that, because some children need that, but somehow it is kind of hidden into, it's kind of disguised into normal life a bit more here" (Julie, HU).

The extract above, whilst depicting the natural feeling that the hospice created, also suggest that there is an underlying perception that things were hidden. Emma (HU) whilst referring to the criteria that the hospice has to meet, suggested that *"it's done in such a way that you don't really realise that it's going on...the kind of. . . everything is focussed on keeping your children happy, and everything else that has to happen, happens alongside that"*. Charlie's (HU) words also suggested that the physical outward appearance of the hospice, *"a kind of an officey building"* added to the illusion created, *"there's nothing on the outside that really shows what's inside"*. This sense of masked identity continued as all of the parents, who had experience of a hospice, recognised and acknowledged their view that there was another side to a hospice. Many parents referred to it as a *"hidden side"*, a place within the hospice that they explained they, as yet, had not needed to *"venture there"*, a *"side where children go and you know it is for the end of life"*. Felicity (HA) described this as *"two identities"* but then she added *"but the other identity is sat behind everything else, type thing"*. This apparent acceptance that the hospice had two roles meant that parents who have experienced respite kept returning to continue to enjoy all that the hospice offered:

"A hospice does two things, its, it does a double job a dual purpose, that there are, the people in there that have, more, different needs to you, maybe reaching the end of their life, need support, but I see, it operates in two ways, and it is also a support centre" (Sharon, HU).

Whilst all of the parents acknowledged that end of life care occurred at the hospice, for each of them it was something that was in the future *"it's kind of like, you know it's coming, that could be months, or whatever"*, but the delight in not having to access that part of the hospice was evident in the words of Katie who said:

"They've done a fantastic job in masking the real reason for the place, and you can't see any of it. It's there. But you can't see it. And it doesn't matter how long you stay there, you still can't see it" (Katie, HU).

Also evident in Katie's words is the suggestion that respite is not the "*real reason*" for the place. This is in keeping with the paradox created in which living was experienced in a place meant for dying. In terms of respite and end of life care there was physically no differentiation in space within the hospice but for the parents there was the suggestion that two separate spaces existed. For some parents this was related to the quiet room where children lie when they have died. For some parents like Banu (HU) there was a sense of anxiety related to that separate space "*you have to pass it, and you always think about that room, and then it's like a split second, and then you, you're down the corridor off to your pool with your daughter*". For other parents like Katie the anxiety was not evident in her words but the need to avoid the separate space was evident:

"Although you know it [death] goes off, because you know what they are there for, the word hospice is in itself an indicator of what it is, and although all the kids there are evidently really poorly, [pause] the ones that are there for the end of life care because they are looked after in their own rooms because they are, you don't even walk down the corridor, when there's kids in that corridor" (Katie, HU).

The idea of separate spaces continued in the narrative of other parents. Sharon (HU) talked of the presence of a door, "*I think they do very well at what they do, and I think it's also part of the reason that you trust them, because you know that when you need that, that closed door is there for you*". Whilst Sharon was also acknowledging the fact that at some point in the future the end of life side of the hospice would be her experience, for the majority of parents the feeling was that they wanted to continue to experience the protection of knowing that end of life care was not overt at the hospice, "*we've been there when there's children that have only hours to live, and it still doesn't feel like that*" (Josie, HA).

There were two parents in the hospice user group who found it difficult to reconcile the idea that the hospice was both a place of respite and a place for end of life care. Fran (HU) described the hospice as "*obviously there's a confused offer, isn't there, either it's a respite place, or it's a palliative care place*". Sharon (HU) whilst recognising that the hospice had a "*dual purpose*" and was "*operating in two different ways*" felt that it "*doesn't always work*". However, the opposite was true for the majority of the parents, Felicity (HA) described how her misconceptions changed after a visit to the hospice, "*it's a place for dying, that's absolutely what you think, but once you go, and actually think, no it's not, It's you know, it's*

so much more than that, actually more so than the other bit, you know what I mean". In a place where the initial expectation was tears and sadness, the majority of the parents felt it was a "happy place to be" (Amy, HU). Josie's regret that she did not take up respite services at the hospice earlier than she did were reflected in her words:

"[the decision] we put off, because we didn't want to go to a hospice. The hospice is the place where you go to die, and that's it. That stigma that's attached is so wrong. Because as soon as we went, we were like, we should have done this a year ago" (Josie, HA).

Linda's advice for parents who had no experience of the hospice, sums up the experiences of hospice use:

"Not to be put off by the word hospice. To actually put your foot across the threshold and go in, and go and see what there is available. And, just say, 'yes there are children that die there', but actually ultimately, it's a happy place, it's a calm place. You are properly looked after and cared for, and it's a place for all of you to have a break" (Linda, HU).

4.3 Conclusion

This chapter has provided insight into the theme identified as Coming 'Home'. Accepting respite help is not an easy decision for parents and it takes time. Parents had to overcome various internal struggles and battles before they were at the point of acceptance of respite. In searching for services parents described certain characteristics which helped create in them a feeling of belonging and made it easier for them to cross the threshold into the respite world. For some of them this meant entering the hospice, parents are surprised to find that rather than reinforce their negative preconceptions the hospice is a place of life, where every day counts, where the vision is to look forward, to enjoy living and being alive.

A paradox exists which meant that having a child with a life-limiting condition allowed entry to the hospice, which then became for the parents and child a place to belong and a place which offered parents a sense of relief and regeneration. However, the reality is that the hospice was a place with two sides, with one side, end of life care, mostly hidden from them. It was a place that was different from what they anticipated, a place where they found comfort, a place like home, a place where they didn't have to think about the

potential future and where they could concentrate on living in the 'here and now'. The next chapter will present the findings of the second theme described as, 'This is Living Now'.

Chapter 5 Findings: This is Living Now

In this chapter a detailed account of the second theme ‘This is Living Now’ will be presented. Two core categories were identified, ‘Balancing the Scales’ and ‘Creating Our Own Normal’. Figure 5.1 illustrates the categories and sub-categories for this theme. Having a child with a life-limiting condition meant that ultimately life for parents was different from what they had planned or hoped for. This chapter is focused on the difficulties and challenges that parents faced as they came to terms with the restrictions that caring for a child with a life-limiting condition presented. At the same time parents described how having a child with a life-limiting condition meant that they also had to cope with various types of loss in their lives. In addition to loss of the ‘normal’ child that they expected, parents described loss of identity, loss of friendships, loss of potential and loss of the future they had planned. Many found that their life was not their own, instead life was defined by the needs of their child and the multiple roles and identities that they adopted in order to manage their child’s care.

Parents perceived their lives with a child with a life-limiting condition as different to those of parents of other children. Some parents described their lives as not ‘normal’. Many parents described their life as a fight, dictated by routines and schedules, spent chasing access to services and resources that they felt their child was entitled to and dealing with the loss of a ‘normal’ life. The idea of ‘This is Living Now’ depicts the overall sense that for parents and families with a child with a life-limiting condition, they are living life as it is now, not as they had planned it. Shona’s words typify this sense of living in the now:

“Rory may not live as long as an average person perhaps, his everyday life is limited, if that makes sense, so we do live by the seat of our pants, in so far as we are trying to do things to make sure we’ve done them, but not that we’re thinking he is going to go soon, or anything like that, it’s just that, if we wanted to do it, let’s just do it, as long as we’re not breaking the bank, do you know what I mean? It has changed our perspective on how to live life, put it that way, I think once you realise that, you know, none of us might be here tomorrow, but not just Rory it makes you think about everybody” (Shona, HU).

Parents balanced the impact of the restrictions and loss that they faced in caring and managing for their child with creating a life for them which captures the best of

everything. Aware that life for them is *'far from normal'* and to gain a new sense of equilibrium they take control of their life and create their own normal.

5.1 Balancing the Scales

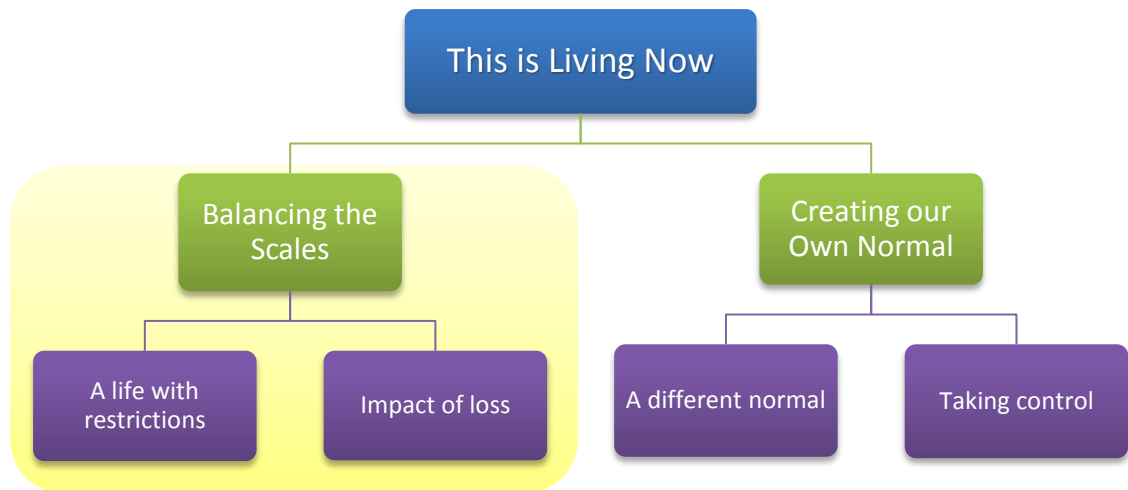


Figure 5.1 Theme 2 - This is Living Now: Core category - Balancing the Scales

In this core category parents discussed the impact of restrictions in their lives from having a child with a life-limiting condition. Parents described how they felt their lives were closely timetabled, how everything needed to be well planned and organised, how everything was more intense, with little spontaneity, and often little chance for diversity from routines and schedules. The pressure of constantly readjusting to the impact of these restrictions forced parents to fight for services and resources that they believed their child was entitled to.

Parents also reflected on how they had to deal with losses that many of them experienced as a result of having a child with a life-limiting condition. Parents described how consumed by caring for their child they adopted many new roles, and in doing so, for some this meant they lost sight of their own identity. Many parents explained how the losses that they experienced were like a bereavement. To try to balance their lives parents explained how they had to counter balance the effect of restrictions and loss. This meant that they had to come to terms with the fact that their child and ultimately their future was different from what they had hoped and planned for.

5.1.1 A life with restrictions

All of the parents described their lives as restricted and governed by intense adherence to time and schedules. Pauline (N-HU) explained how *“you’ve got to be thinking and planning for what you want to do in three months’ time”*. Whilst Ruth acknowledged that life with children is about routines and patterns *“we’re all led by diaries to some extent”*, she also alluded to the fact that her life with a child with a life-limiting condition had less choice and perpetual organisation meant that her life was different from other people around her:

“Having a child like Martha, your life is organised for you, and everything is led by your diary, because all the services have to work on a rota, I understand that, but that does mean that your life is mapped out for, two months, three months ahead, and actually in the kind of the real world, how many people know what they are doing in two or three months’ time” (Ruth, HA).

Whilst many of the things that parents do in caring for their children are integral to the parental role, parents in this study described how these were at a much more intense level and continuous with a child with a life-limiting condition. Pauline said:

“We were just so stressed out from obviously the very beginning, massive, massive change when you have a baby anyway, but a massive change when you’ve got a child with a disability” (Pauline, N-HU).

Pauline (N-HU) continued to describe how *“half your life, well, half your day, is taken up with doing just a few jobs”*. For John (HU) there was *“so much stuff to contend with, it’s a constant, you’re doing stuff all the time”*. Caitlin described how a simple task seemed so much bigger:

“You’ve always got something on, and if it’s not that you’ve got to go and pick his nappies, or his bits, prescription up every week, it’s all sorts, and it’s not just easy, when I pick a prescription up they laugh at me at the place, because I walk out with two great big carrier bags” (Caitlin, N-HU).

Many of the frustrations parents felt were as a result of meeting scheduled appointments for their child. Caitlin (N-HU) described how having *“24 appointments in 17 days”*, outside of the home setting with her son Peter made her *“just kind of lose the will to live”*. Ruth (HA) concurred with this view but also commented on the rigidity that living to certain

service specifications placed on their lives. She explained, *"but I get sick of that clock watching, got to be back by this time, got to be, you know, there's no flexibility for being late is there?"* This constant pressure of living, influenced by the inflexibility of intense schedules and routines created in a number of parents a sense that there was *"no spontaneity"* in their lives (Edna, N-HU), with one parent even describing their life as *"almost sterile"* (Ruth, HA).

For others living with restrictions made them feel their life was a struggle. Many parents, like Bernie (N-HU) and John (HU) described how they constantly had to *"fight for everything"*. The persistence of the fight was depicted in the words of Caitlin (N-HU) who explained how *"it just goes on and on and on, and you fight for everything, and you repeat yourself so many times"*. Many parents described the challenges of accessing resources such as equipment. Pauline (N-HU) described how it had taken eleven weeks to get a new wheelchair for her son Fred. The constant chasing of services and resources was both frustrating and tiring. Hannah explained how waiting for a particular piece of equipment made her feel:

"I rang them every single day for two weeks, and nobody even picked up the phone, but the answer phone message told me I was first in the queue be patient, ...you've just got to keep on and on and on, it is exhausting" (Hannah, HA).

For other parents the fight was associated with relentless pursuing of people as Larai explained:

"there's a very long delay getting back isn't there, I don't know, when you're trying to get hold of people, and stuff like that, you can spend days sometimes can't you. There's a lot of chasing up" (Larai, N-HU).

When telephone calls were not returned, John (HU) said *"I find it frustrating trying to get stuff done it drives me mad, really does, nobody, nobody will call you back"*. This constant and repetitive chasing of services left parents feeling exhausted, Abi (HA) highlighted how *"not only are you tired looking after your child, you are tired chasing round"*. Several parents used figurative expressions to highlight the intensity of the fight, alluding to the idea of a war zone. Abi (HA) described her life as a *"battlefield"* whilst Edna (N-HU) commented that life was *"a battle"*. Larai (N-HU) explained how she felt *"imprisoned"* in her own home because she had to conform to appointment times made by health

professionals who visited her daughter at home. Caitlin (N-HU) described her life like a *"minefield"* suggesting she had to avoid the challenge of obstacles in her way as she tried to manage life with her son Peter. She also explained how it was difficult to balance her day because of the increasing numbers of professionals visiting her son Peter at home.

For some parents, the pressure of feeling they had to fight and negotiate access to resources made them more tenacious. Edna (N-HU) explained how she felt she was *"making a pest"* of herself, whilst Verity (HA) described herself as, *"I'm a bit of a battle axe!"* as they both pursued people and services for their children. Ruth (HA) described how when it was suggested she access a particular service she *"started to fight back ..., because I was kind of thinking No!"* Pete (HA) when referring to his wife and himself said although, *"we're not the sort of people who stamp our feet and scream and shout and make a fuss, that kind of is what you have to do"*. Edna (N-HU), when talking about life before the birth of her son Thomas, admitted that she was now a *"completely different person to who I was before, [then I was] more intolerant"*.

Balancing the need to fight and negotiate services was challenging for some parents. One mother described, how over the years, she had learnt to pick her battles:

".....sometimes you do have some battles, but on the other side of that I am very much a - pick your fights, you know, I will fight on that one, but you know what, oh well, we will let that go" (Felicity, HA).

However, there was a sense that, despite their tenacity, some parents were forced to complain to achieve services or resources that they believed their child was entitled to. Hannah (HA) explained: *"It got to that stage where I had to complain about it, before somebody would do anything about it"*. Verity (HA) explained how despite finding appropriate services for her daughter Jess, the fight continued as she explained: *"It has been a real battle. We know what services are out there, we know what she needs, but trying to get it to work and in place has just been ridiculously exhausting"*. Describing services as more *"complex"* than the *"complex needs"* of her daughter Jess, Verity (HA) explained how she had no option but to complain because she believed Jess was not getting the services she was entitled to. Andrew (N-HU) described another situation where he and his wife experienced many difficulties getting their son Thomas into their local school and how

when “we wrote to the MP, head of service, miraculously a space has opened up in [name of school] for him in September”.

In addition to coping with the restrictions described above, parents continually had to deal and come to terms with the impact of loss in their lives.

5.1.2 Impact of loss

Having a child with a life-limiting condition meant that life for parents changed significantly from what they had thought it would be and planned for. Edna (N-HU) highlighted the enormity of the impact saying “when Thomas was born, everything was turned on its head, everything we planned for or thought was going to happen, changed”. Shona (HU) explained how “you’re having to accept, trying to accept the fact you haven’t got the child you thought you were going to have”. Bernie’s view was that her future had been stolen from her:

“....it’s when you’re expecting a baby, and then you get your child, and then you find out that there’s something wrong with them. You just feel so deflated, and so, you might call robbed” (Bernie, N-HU).

This sense of a future being stolen from parents was echoed by other parents like Katie, Caitlin and Verity who described their loss. Katie said:

“I feel robbed of time, I feel that I’m going to be robbed of seeing Paul grow up, he’s never going to get married, he’s never gonna have children, and that has been taken from me” (Katie, HU).

Caitlin (N-HU) described how her son Peter was, “....never going to have a girlfriend, never have children, never going to do this, never going to do that, never going to have their own house, I’m never going to be a grandma”. Verity (HA) questioned “Will Jess ever say ‘I love you? Will she get married? Will she walk? Will she talk?’” Shona also described the effect of loss on her husband:

“He’s not going to watch his son play football, all those things that men and boys do, and I do feel sad about that, and I don’t think I will ever get over that” (Shona, HU).

A few parents compared the loss they experienced as similar to the process of bereavement. Shona described how:

"It's accepting that you're never going to, never going to get over the fact that our child isn't what you were expecting. It's accepting that you are going to have those feelings. It's, for me, I had to go through a grieving process for the child I thought I was going to have" (Shona, HU).

Linda (HU) described the trajectory of both her sons' condition as *"a constant bereavement process"* as they lost *"the ability to walk.....the ability to use their hands. Their lung function goes"*. For Edna and Shona the feelings of loss never abated. Edna (N-HU) explained how for her *"it's as raw probably some days, as it was the first day"*. Shona's described the unforeseeable reaction to grief:

"Even the other day, I went to bowling alley, load of us that went, and one of our friends has got a little boy, same age as Rory, and she held his hand and she was skating with him, and I, I burst into tears, and I thought, 'oh my goodness that should be Rory'.....it's just accepting that you are going to have days when it's like that" (Shona, HU).

Reconciling the complexities and the sense of loss experienced by parents was challenging as one mother tried to explain, *"...there's counselling for bereavement, but we've got loss already in our lives, but he's here. So we haven't lost him, but we have, it's very, very difficult to explain"* (Josie, HA). For some parents trying to balance feelings and emotions with their experiences of loss was difficult. Ruth described how there was a need to continually cope with change. She said:

"After 11 years, you think surely you must have come to terms with the whole thing, but actually everything changes, doesn't it, so it's that constant re-adjustment, and you get to this milestone, and no, she hasn't done any of that, and that constant moving of the goal posts, so you're constantly having to re-adjust" (Ruth, HA).

For some parents there was a sense that the future for their child was unfair. Referring to his son Rob, John (HU) described how *"you don't realise until, until you add it up what he can't do, and what he doesn't do, and all the simple things that you really miss out on"*. When talking about their daughter Lucy, David (N-HU) explained how *"we're sad about what life*

she's got, because she come into the world not knowing this". With Fran there was a sense of bitterness with the unfairness:

"Everyone says you get the phrase, these special kids get given to special parents, but we wouldn't wish it on anyone else, and she's our flesh and blood at the end of the day,we will do anything for her, and you know, what will be will be won't it, but youyou feel sad, it's your own child" (Fran, HU).

Another area where parents experienced loss was in the concept of their identity. Banu's words reflected the feeling that although there was life before the birth of their child with a life-limiting condition, as they as parents became consumed in caring for their child, it became more of a distant memory:

"To kind of be you again you just forget that you are, you know who you are, you know, you're doing it without noticing just looking after.....and you don't think about anything" (Banu, HU).

Pete (HA) concurred with this view saying *"we'd forgotten how to enjoy ourselves, that's the impact of it, and it's not until you look back that you realise that. Because we were, we just got to get on with it".* For other parents, *"having carers and everybody coming in your house, in your space"* (Penny, HU) meant that their life was one with *"no privacy"* (Abi, HA) and your *"home is never your own"* (Caitlin, N-HU). Pauline's perception was more extreme and one where she felt:

".....you can't have a life, I mean, it's like, like before you have a social life, you can pop out for cups of tea in places, you can't do that now..." (Pauline, N-HU).

For a few parents the loss of identity was associated with the inability to work. One mother expressed how having a career was not an option *"I can't work. I want to work"* (Caitlin, N-HU), whilst Mona (HU) explained how she had to continue to work to *"to keep my sanity"*. Fran's (HU) words depict her delight as she described how, having not worked for fifteen years, she had returned to work six months previously and that *"It's good"*.

In caring for their child with a life-limiting condition, parents described how their own identity was overtaken by many other different roles. When talking about her daughter, Larai (N-HU) explained that she was, *"Lucy's carer. As well as Lucy's mum. Do you know what I mean? I know, the two roles are rolled in, are just in-built, but picking those out, is*

sometimes quite difficult". Felicity (HA) described herself in multiple roles, *".....professional mum, not very well paid! (laughing), hours are long! You become mum and carer, health manager, equipment supervisor, social secretary..."*. For some mothers, in the process of caring, the concept of being "mum" was lost. Caitlin explained how:

"I don't think you've got chance to feel like a mum. No. You're a carer, you're not a mum. You're a carer aren't you? That's all you are really. You are a mum obviously but you don't feel like a mum" (Caitlin, N-HU).

Verity (HA) said, *"I'd like to say I'm her mum, but I think I'm also more like a key worker myself, trying to organise the services"*. However, it was not only mothers who expressed confusion in their identity. Pete (HA) described how *"it's almost like I've become two people, I'm a different person at work, I have to be, to how I am at home"*. When referring to his wife Josie he continued *"my work is elsewhere, your work is here, so I can be old Pete at work, and new Pete at home"*. For those parents who had experienced respite at home from carers there was a sense that this added to the confusion in roles. In referring to the carers coming into their home to help with the care of her son Conor, Josie (HA) said *"they come in, they start playing with Conor, and I'm in the kitchen cooking or cleaning up"*. The extent of this confusion is appreciated in the words of Josie as she continued:

"I think it come to when you go over to your son, and he hits you, but he grabs the carer and kisses her. That's when it hits you" (Josie, HA).

Unfortunately for some parents like David and Fran, the multiplicity of roles was something that they were still struggling with and which left them feeling angry. David when referring to his wife Larai said:

"Larai is not here to be a nurse, she's here for a mum, and sometimes, she has all these jobs to do, she can't fit them all, with washing and ironing as well as everything as well" (David, N-HU).

The struggle to provide 'nursing care' for their children was evident for both Verity and Fran. Verity's words depict the emotional strain and how she rationalised her feelings, *"It's heart breaking to think Jess thinks mummy's hurting her. So there is, lots and lots of feelings, but I just have to keep telling myself, it's better that mummy does it, than a stranger in a hospital"*. With Fran however, there was a sense of bitterness:

"It's a horrible, horrible thing to have to do when that's not what you planned, it's not a career that I chose. I'm not nursing, I'm not trained in any kind of therapy,.....we are put in that role, we're given that" (Fran, HU).

Several parents also described the effect on their friendships of having a child with a life-limiting condition. Shona (HU) described how *"we did lose a few friends after Rory was born, because they couldn't handle it"*. Caitlin (N-HU) suggested that friends *"drifted"* because *"obviously there's a lot of stuff you can't do with them"*. In other cases the view held was similar to that expressed by Edna (N-HU) *"I have lost the occasional acquaintance rather than friend who felt so awkward, about having normal children, when we haven't"*. The idea that life with a child with a life-limiting condition is viewed as not 'normal' will be considered in more detail in the next core category 'Creating Our Own Normal'.

Pete's view was that in some cases a lack of knowledge and understanding of life-limiting conditions contributed to the strain on friendships. He explained:

"Conor has completely changed our social circle. Some have been brilliant. Some have come into their own, others, we've completely lost touch with.It's equally upsetting when people you think are friends come out with something as inappropriate and thoughtless, it's just silly. Not that they've been overly rude, it's just down to their own ignorance, and that is just such a massive factor isn't it?" (Pete, HA).

Unfortunately, the losses described above contributed to a sense of isolation experienced by some parents. Bernie (N-HU) commented on her isolation, she said *"you know you are on your own, it's like a lonely world"*. Edna (N-HU) described how after her son's birth *"the first two years we missed everybody's weddings and we never made it out the house, we barely made it out the house"*. However, Edna continued to explain how she was managing to get some balance back into her life as she expressed *"now we are getting a little bit of normality back"*.

In summary, in trying to maintain balance in their lives and a state of equilibrium, as a result of having a child with a life-limiting condition parents were forced to cope with restrictions placed upon them. In response to this the choice was to either *"I buried my head for several years not wanting to admit defeat"* (Ruth, HA) or attempt to balance the scales. For many of them this meant they were forced to fight for services, experienced a

change in their identity, embraced new roles, and coped with the loss of the child that they had hoped and planned for. The choice to balance the scales and live life differently is continued in the next category “Creating Our Own Normal”.

5.2 Creating our Own Normal

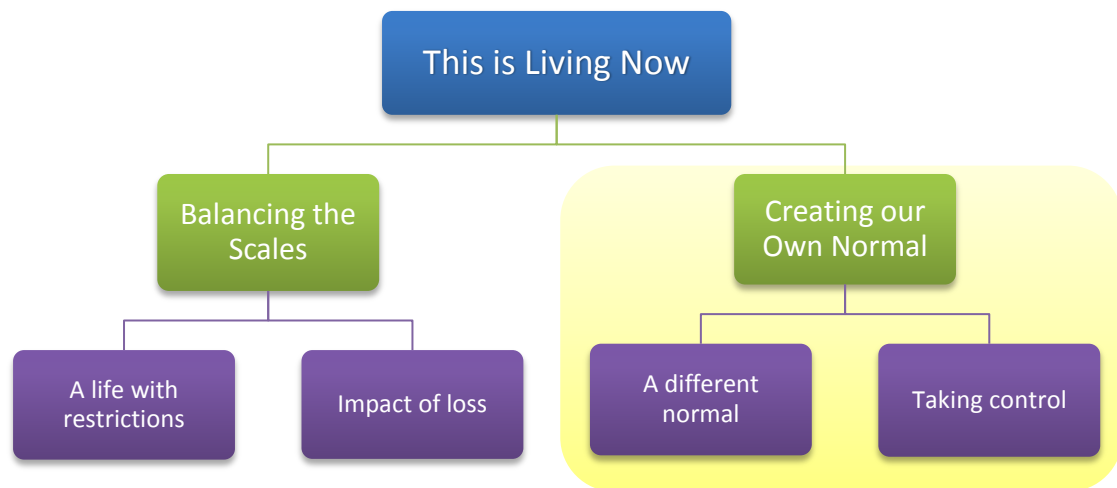


Figure 5.2 Theme Two - This is Living Now: Core category – Creating our own Normal

In this core category parents perceived that their world was different from those around them. Parents alluded to the notion of two different worlds, their world and the ‘real’ world. The ‘real’ world was not inhabited by parents like them with children with life-limiting conditions. Parents viewed their lives and the lives of their children as different to other parents, children and families in the ‘real’ world. This differentiation in worlds meant that parents in this study perceived their child and their lives as not ‘normal’.

However, there was a sense that both worlds ran in parallel, and at certain times and in certain situations, parents got a glimpse of the ‘real’ world. For some parents this was when they were able to access respite from caring for their child. For others, whilst appreciating the differences between themselves as a family and those of families around them, the sense was that parents actually sought a feeling of ‘normality’ in their lives and therefore created a little of the ‘real’ world in their world. Integral in this pursuit of

normality was the desire to ensure that life for the rest of the family was more in keeping with those in the 'real world'. In order to create a sense of normality in their world, in addition to balancing the scales previously described, parents talked of needing to take control of their lives.

For some parents this meant adopting new key roles, other than being a mother or father, in order to manage and control the care given and offered to their child. For some it meant a change in perception, attitudes and coping abilities, and for others it was about choice and independence. With the group of hospice users there was also a sense that by accessing respite at the hospice for a short time parents achieved some normality, despite the fact that respite is not on offer to parents in the 'real world'. As parents continued to pursue normality they also made suggestions for service development.

5.2.1 A different normal

As described earlier, for all of the parents, life with a child with a life-limiting condition was different from what they had planned. For a few parents there was the feeling that this meant that they were now part of *"a different world that you are shut out from if you don't have a special needs child and you're in it if you have got a child with a life-limiting illness"* (Fran, HU). Caitlin (N-HU) whilst describing her life with her son Peter alluded to the fact that she had two lives, one with her son and *"...then you've got your other life going off"*, her 'normal' life as a wife and daughter. Ruth (HA) simply viewed her life as *"different"*. For many other parents the differences were defined in their perception of what was a 'normal' child. David, acknowledging differences when referring to his daughter Lucy said:

"She's never going to be like a normal child, but we just take it as it comes with her really, we will do the best, as in provide the best for her, she given us something different really, so, we just, try and make the most of it" (David N-HU).

For Edna (N-HU) normal was what *"able-bodied parents with able-bodied children have"* whereas in her life she said *"it's not what we have"*. She then continued to explain how after the birth of Thomas' healthy sister she perceived that *"people have felt more comfortable with us since we've had Janet so there is half of you normal"* (Edna, N-HU). Shona (HU) concurred with this view that within families, a child with a life-limiting condition was different from their brothers and sisters. Shona (HU) identified her son

Rory as *"not normal"* but continued to explain that this was because *"I'm comparing him to his sister perhaps, who's, she is normal, you know what I mean"*.

The pressure to do normal things came from the desire to be like other families. Ruth (HA) described her life as *"standing still"* compared to others around her *"everyone else around you moves on"*. She continued by describing her perception that this was in part due to the fact that *"their children can do kind of things for themselves"*. Caitlin (N-HU), when talking about her son Peter, commented *"there's a lot of stuff you can't do with him"*. The restrictions that parents experienced by having a child with a life-limiting condition, (described earlier), contributed to the sense that life was not 'normal'. Fran (HU) said *"If you had a normal life, normal child, normal family..... you wouldn't have to go through the hurdles of trying to access things"*. Referring to the concept of things not being all-embracing Charlie (HU) commented that *"in an ideal perfect world, everything would be inclusive, but it isn't like that"*. For Jane (HU) this meant that *"we could never go out and do anything. We could never just do what, you know, what you do as normal families"*.

Andrew explained how his life was different because of the restriction experienced with holidays:

"In the office at work, you hear people saying they are taking their children to Disneyland, or they are going on this holiday or that holiday, and they are going to leave the kids with their grandparents, and, have a whale of a time, fantastic, and you think, well, we can't do that" (Andrew, N-HU).

Having other children also added to parents' pressure to pursue normality. Josie's (HA) upset was evident as she talked about *"depriving of the rest of your family"*. In Edna's (N-HU) case the decision to have a third child was based on the fact that they wanted Thomas' 'normal' sister to *"have a normal sibling relationship"*. For Ruth (HA) the pressure of coping with her daughter Martha and her sister meant that she was *"always dividing yourself between the two of them and trying to give everything to everybody"*. Like Ruth, Verity was very aware that looking after a child with a life-limiting condition often meant that her other children missed out; her upset was evident:

"When I think about the impact it's having on her sisters, that just breaks me, they are missing one to one time with me, because I'm having to co-ordinate services for their sister" (Verity, HA).

The sense of brothers and sisters missing out continued with other mothers like Fran and Charlie. Fran (HU) described how she felt that her other children are often forgotten *“Chloe is one of three. There isn’t just her in the family, and people forget that quite often”*, whilst Charlie (HU) said *“we’ve got four other children, you want to just do normal things, it’s like trying to make some kind of normality for them”*. Felicity’s and Verity’s words, when referring to aspects of care, were a reminder of how inappropriate it was for brothers and sisters to witness various episodes of care. For Verity (HA) this was related to breathing support, *“our youngest daughter, she’s 7 years old and she shouldn’t have to know what an NPA is”* whereas, for Felicity (HA) *“it’s not normal for me to be doing drugs and tube feeds and those sort of things”*.

Whilst one mother explained how it was not normal to take a child to somewhere like a hospice for respite, *“it’s completely abnormal to go away for the weekend to a children’s hospice”* (Felicity, HA). It was evident that the hospice facilitated time for parents to spend with each other or their other children and gave them a glimpse of normality. Jill explained why she left her daughter Sonya at the hospice for respite:

“We did leave Sonya because we felt it was really important to give the other two some normal time, to be able to do activities that you can’t do with Sonya, because she is a wheelchair user” (Jill, HU).

Charlie (HU) concurred with this view that the hospice enabled parents to spend time with their other children doing normal things, *“we’ve got four other children, you want to just do normal things, I mean there’s so many places, my daughter is in a wheelchair, she’s 100% dependant, doubly incontinent, it makes life very difficult”*. With reference to his daughter Kas, Amir (HU) said the *“hospice just gives you time to be you again, to do things you want do without worrying about her”*. Fran (HU) described how the support and activities offered at the hospice for siblings *“compensated in some sort of way”*. For some parents like Banu, respite at the hospice became something that the family experienced together. Banu explained how:

“It’s just part of the normal, part of her routine, once a month she goes, and she has a good time, we get fed and watered, which is nice because we don’t have to do the cooking, and her sister accesses the sibling groups” (Banu, HU).

There was a strong sense that achieving some normality in their lives was very important for parents. Edna (N-HU) described how going to the park for the first time with her son Thomas meant that his sister could *"have a bit of normality as well"*. Verity's (HA) desire to create this at home was evident *"to have some kind of normality amongst everything that is going on, to be able to just live a family life at home"*. Consequently because the majority of parents perceived that their lives were far from normal, they created their own parallel normal. When referring to his life David explained (N-HU) *"this is our normal, but this is far from everybody else's normal"*. Katie (HU) described how it was still possible to have a *"a good life"* where *"you can still do everything but in a different way"*. She commented that her husband could still have fun with their son Paul but in a *"different way, it's not any less, it's just different"*. Josie's words reflected a change in perspective, from an old normal to a new normal:

"That feeling of things being stolen has kind of, gone, in the fact that we know we are where we are with Conor, you know that normal life at the time, what we saw as normal life, that had suddenly been ripped out from under us, our future had been stolen and that is how it felt. Our future is different now" (Josie, HA).

Katie commented on the importance of sharing experiences like family holidays. She said:

"It's like someone said to us about going on holiday, 'how on earth can you go on holiday?' And I say, 'crikey, Paul still needs to go on holiday, it doesn't matter', 'but isn't it a bit awkward and a bit of a faff', and I'm like, 'no, it's just different, it's not any worse, any better, It's just doing it differently' " (Katie, HU).

However, for some parents accepting the concept that their lives were a different 'normal' remained a challenge. Fran (HU) explained *"this is our norm now. It shouldn't be our norm, but this is our norm"*. With Ruth the sense of acceptance mixed with resignation that this was her life now was evident as she explained:

"I think maybeyou do come to accept things, and I think also the danger is that that becomes the norm. So actually you forget what, what it's like, or what it might have been like, because you forget that, life could be a lot simpler, because now 11 years later, I can't remember, what, what life was like, and in a way how simple life was" (Ruth, HA).

Shona whilst acknowledging the positives of having her son Rory and how it *"has changed our perspective on how to live life"* expressed how she *"will never stop wishing he was okay"*. The extent of her desire for normality was highlighted when she explained how when

pregnant with her second child, she explained how *"half of me wanted a boy so Jim [husband] could experience a real boy"* (Shona, HU). As parents continued to long for 'normality' they found that they needed to be more in control of many aspect of their lives.

5.2.2 Taking control

For some parents, like Ruth and Edna, taking control was linked with the desire to maintain their independence. For Ruth (HA) this meant that she wanted to be *"able to make your own choices as opposed to being done to all the time really, and having your life run by other people"* and Edna (N-HU) explained how she wanted to *"Let me get on with it, I will get on with it, you do what you're doing, I will get on with this"*. For others like Hannah (HA) and Verity (HA), there was more of a sense of deliberate action, something that they had to do. Hannah said *"my life doesn't run unless I run it"*. Verity explained how the pressure of making time meant that her day began two hours before everyone else in the house so that she then had time for her other daughters:

"Most mornings I will set my alarm and try and get up at 5 o'clock so I've got a two hour window before I have to do Jess's care needs to try and squeeze as much in so that the girls don't pay for it after school" (Verity, HA).

In order to manage her daughter's care Verity also described how she had adopted the role of key worker, *"I have taken on that control role and I know if I'm in control and I know what I am doing it can be managed"*. This need to maintain control and advocacy is depicted by other parents like Hannah (HA) who said *"you've got to shout for your child as nobody else will"*. Edna (N-HU) described how she *"proactively managed"* her son's care.

Taking control was also related to parents' attitudes and ability to cope with their life. Whilst there was an appreciation that *"different days and different challenges make you feel differently"* (Pete, HA), some parents described how they made an active decision to view their situation positively. Josie described her decision:

"I think the turning point was Conor came home from school one day, saw us, and started crying. I said this is ridiculous. He's got to stop seeing us crying all the time. He's picked up on us, and that's got to change" (Josie, HA).

Josie (HA) continued to explain her change in attitude, *"for me personally it was like a mind over matter thing, that me not coping is failing him, failing Conor so I'm not going to allow*

that to happen". John described how he no longer deliberated over decisions that needed to be made:

"I don't take it lightly, but I think once it's done, it's done, and early on, you used to talk through it for ages and ages about the things you do, but now it's either yes or no, and then that's it, you have to kind of draw a line under it" (John, HU).

For Felicity and Shona the choice adopted was to make the best of every situation. Felicity's (HA) words depicted her character and attitude *"I am a, 'what will be will be' if I can make it better then I will and we'll go with the flow"*. For other parents taking control meant perseverance, Hannah (HA) explained how *"you can't lose faith at the first hurdle you've got to keep plugging away,if you gave up at the first hurdle it wouldn't do Daniel any good would it?"* Ruth's (HA) words demonstrated the need to overcome barriers that affected the child's care *"I will just plough on until someone puts an obstacle in the way, and then you find a way around the obstacle won't you"*.

Whilst there was some confusion as to how personal health budgets worked, there was a common view held by parents that they would offer them *"more control, and we'll have a better say on the carers that are coming in"* (Edna, N-HU). Several parents described their personal experiences and the benefits they saw to this approach to care. Pete (HA) explained how it meant that as parents they could *"employ a care company so we've not got the hassle of the holidays and staffing levels"*. For Bernie (N-HU) it meant that relationships with carers were fostered as she knew the two people she had chosen to be carers for her son Joshua. Both Bernie's and Ruth's words reflect more of the benefits of being in control and having a choice. Bernie (N-HU) said with *"your own team, you can tell them when you want them, and if you want a lie in on a Sunday, you can"*; for Ruth (HA) it meant being able to *"buy in the services that actually suit us"*.

For those parents in the hospice user group, the decision to use the hospice was influenced by the concept of taking control, thereby offering choice to the parents. Julie (HU) described how at the hospice *"there's as little or as much as you want"*. Amy (HU) described how the hospice *"allowed you to go and do what you wanted to do"*. For hospice user parents like, Amy, Paul and Jane using the hospice meant they could *"step back"*, *"catch a breath"* and have some *"quality time"* with their other children. The desire for some independence for themselves and for some quality 'me time' was also present with other parents who were not hospice users. For Caitlin (N-HU) the desire was for

something simple, she wanted to *“get a bit of tea and sit down and eat it, without having to keep getting up and down”*. Pauline (N-HU) described how *“I would like to go out tonight without having a plan because everything has to be planned”*.

A few of the parents also reported how the hospice facilitated independence in the child. Ria (HU) explained one of the reasons for taking her son to the hospice for respite was about *“giving him some control”*. She continued to explain how he had *“made good friends”* with other young people, and because they had the same condition *“they understand”*. Katie (HU) suggested that her son Paul *“needs a break from us as much as we need a break from him sometimes”*. For Ruth (HA) it was important that her daughter Martha experienced *“socialisation”*, which she believed the hospice could offer because *“there were other activities going on, and other children, and Martha can join in”*. In addition to the affected child many of the parents expressed how respite at the hospice empowered siblings. Ann’s words clearly described the importance of having support strategies for siblings:

“I think it is so important for siblings to have other children of similar ages, that they might go, ‘You know what, it’s really shit, I just want to be able to do this with mum but I can’t because we always have to do this first’, or whatever, and for that other child, to not bring on an adult perspective like mum does a lot for the other child, to go, ‘You know what, it really pisses me off as well’, or whatever, they can just let it out, with people that may feel in a similar way” (Ann, HU).

Julie’s (HU) words regarding the value of the hospice for siblings was a view held by many of the parents in the hospice user group:

“....because I was always very concerned that our other children wouldn’t feel resentful, that the two that were poorly were taking up all the attention and the time, and life, so actually Woodlands was very significant in being able to build that into them, and I think the sibling days that they did come on when they were younger, helped them to see that they weren’t on their own, that there were other kids that were in the same position, and I think that was quite valuable as well” (Julie, HU).

Ultimately taking control culminated in ‘survival’ and Felicity (HA) explained that *“to just survive, (laugh), because some days it does feel a little bit like, oh my god, I’ve survived, tomorrow is another day”*. Despite anxieties regarding the identity of the hospice and that

ultimately it was a place for end of life care, the hospice continued to offer a support mechanism and a means of survival, “a life-line,” for many of the parents in the study. However, the relief experienced and the normality the hospice offered parents was only temporary and lasted for as long as the respite did. Amy’s words reflected firstly her sense of relief and then her sense of realisation:

“Finding the right service, yeah, because you can actually walk away, and hand him over totally, 100%, everything, I’ve never yet found another service like that, where I can, [pause], I just feel like when I walk away, I just handed over, and then usually I just cry, [pause] I just think, this is just for a couple of days, and then it all comes back” (Amy, HU).

The difficulty in maintaining control was demonstrated in the view that despite finding respite services like the hospice, the service often failed to respond to the needs of the child and family which left parents feeling discouraged and disillusioned. Ruth’s (HA) words reflected her perception that families were expected to fit in with services and what was offered “being able to have services that suit you as a family, rather than being put into a box”. Many described the limitations on choice of available nights for respite, particularly at the hospice. Penny’s experience was one where she felt unsupported at a time of need as she explained:

“Wherever you see hospices on the television, and they are talking about children’s hospices, they always seem to describe the fact that if you’re having a rough time, you can ring up your local hospice, and say I’m having a rough time, I really need a break, and they will book you in, and you go for a few days, and everything is lovely and rosy, in reality that doesn’t happen. In reality you have to book now months in advance to get a bed, and if a crisis happens, even then, the chances are you’re not going to get in” (Penny, HU).

Parents continued to express a desire for a service that was responsive and supportive, a service with the characteristics described earlier. Some parents expressed a desire for respite to be offered either at home or in smaller facilities geographically located closer to the family home. Parents described the desire for carers who knew their child and who could provide care for their child at home. For those parents in the hospice user group the suggestion was that carers who knew the child and cared for them in the hospice would ‘follow the child’ and provide care at home. This translated into care provided not only during crisis situations but also regular outreach and support in areas like babysitting, to

facilitate time for a parent to play with their child or help to go out for a walk. As a result of the relationships and bonds built with carers in the hospice parents also wanted the reassurance that when end of life came, those carers with whom they had bonded, could be with the child either at home or in the hospice, dependent on the parents' wishes.

5.3 Conclusion

This chapter has described the findings of the study which have provided insight into the second theme identified as 'This is Living Now'. In trying to maintain a balance in their lives parents are constantly forced to overcome many restrictions. Parents try to cope with the pressures that adherence to schedules and the need for constant organisation places on them. Many of them are forced to fight for services and resources in a world where many of these are limited and scarce. In addition to the many restrictions that they faced, parents were coping with the constant need to overcome the impact of loss in their lives; loss of the child they had hoped for, loss of potential in their child's future and loss of their identity as parents. In all of this, the parents were aware that life for them was very different to that of parents around them.

What they perceived as 'normal' was not what they had and because of this they perceived the world that they lived in as different from those parents who did not have a child with a life-limiting condition. Many of them yearned for normality and what parents with 'normal' children have. In order to gain some sense of equilibrium in their lives with that of the world around them the parents created their own normal. By taking control they achieved a life that was different from those around them in which they were "*living day by day*" whilst appreciating that their "*future is tomorrow*" (Ruth, HA). Whilst respite services such as the hospice offered parents either some time to do normal things as a family with their child without the pressure of caring for them or time away from their child, the sense that certain characteristics needed to be present prevailed. Ultimately the decision to live life as it was now required parents to accept the restrictions on their lives, make each day the best it could be and embrace the future and 'move forward' to tomorrow. The next chapter will present the findings of the third theme described as 'Moving Forward'.

Chapter 6 Findings: Moving Forward

In this chapter a detailed account of the third theme 'Moving Forward' will be presented. Two core categories were identified, 'Living with Uncertainty' and 'Uncharted Waters'. Figure 6.1 presents the categories and sub-categories for this theme. 'Moving Forward' portrays the idea that despite the complexities of life and the many obstacles that parents of a child with a life-limiting condition face, life for them moves forward. Whilst there is a very clear sense of direction of travel, into a future where their child gets sicker and inevitably moves towards the end of life, they continue to move forward. Their future as parents is uncertain and because of this they live in 'the now'.

For some parents the journey with their child was much longer than they ever anticipated. Out of the 36 children whose parents participated in the study, 13 children were 16 years of age or older; and 9 children were aged 11-15 years. The theme 'Moving Forward' also portrays the notion that for many parents in this study whose child with a life-limiting condition was surviving beyond the parents' expectations, transition into adult services was either imminent or had occurred. This posed new challenges for parents particularly in the choice of adult services available for them to access with their son or daughter. However, the consensus was that in the majority of cases adult services were not the solution for this group of young people. Despite being the right age for transition, some of the young people had such poor cognitive function that their parents believed staying in children's services was more appropriate. For those parents whose children were young enough not to be facing the prospect of transition to adult services, their fears for the future were associated with other transition points in their lives.

With respect to the young people, who were physically disabled but cognitively able and who accessed the hospice, questions were raised by the parents as to whether the hospice was the right environment for them to receive respite. Parents believed that their teenagers and young adults were trying to live as normal as lives as possible and integrate with many of their peers, but at the hospice they were the '*part of the jigsaw that didn't seem to fit*'.

6.1 Living with Uncertainty

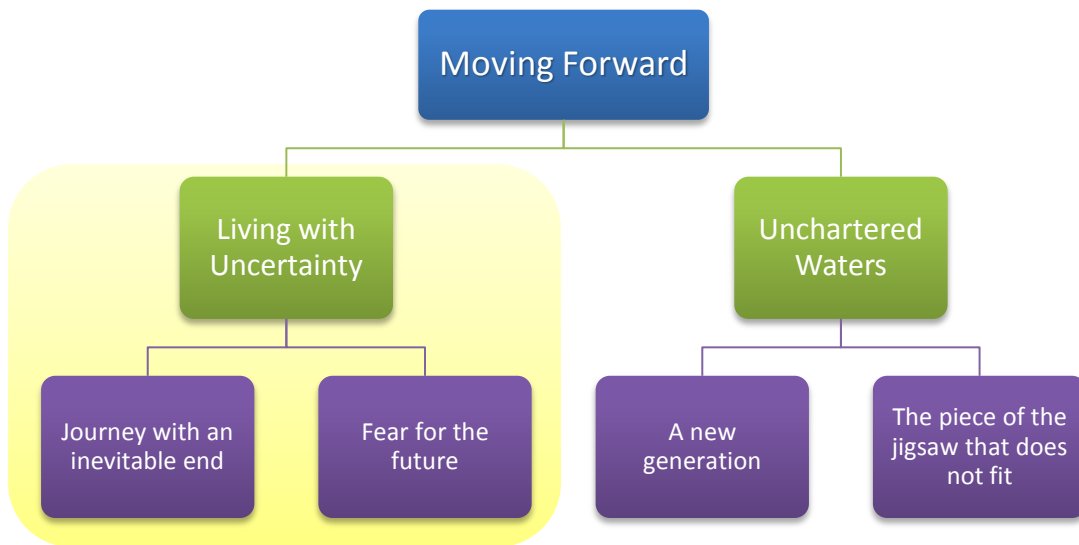


Figure 6.1 Theme Three – Moving Forward: Core category –Living with Uncertainty

For parents living with a child with a life-limiting condition was akin to travelling on a journey. In the last two chapters the challenges that parents faced on this journey have been described. Despite many parents agreeing with the view that life was inflexible and confined by routines there was also a sense that life with a child with a life-limiting condition was also unpredictable and uncertain. Whilst all the parents appreciated that their journey was one with an inevitable end, the death of their child, not all parents wanted to discuss this, particularly those in the non-hospice group. Despite parents also acknowledging that the anticipated length of life for their child would be shorter than normal, parents were uncertain in terms of the progression, path and timing of the end; this uncertainty was difficult to live with. Parents also had many anxieties and fears about the future for their child with a life-limiting condition.

6.1.1 Journey with an inevitable end

Felicity's (HA) description of her journey demonstrated both the unpredictability and the inevitability of the journey. The picture created by her words is of a journey where parents and child would experience many troughs and peaks along the way, *"I go with the journey, well actually it's a roller coaster, and sometimes you feel like you can't get off it"*. Verity (HA) concurred with this and admitted that in her life *"everything is kind of, been a*

roller coaster". Despite being planned and organised, Felicity (HA) also expressed the unpredictability of day to day living, she said:

"I got up this morning with a blank board on there, I've now got a list of 3 or 4 things on there, which have all occurred at some point this morning, which I've got to sort out, do you know what I mean, so it's that roller coaster" (Felicity, HA).

In describing the unpredictability of the course of her son's illness Abi also compared her emotions to a rollercoaster ride and said *"you're up down, up down, you know, you don't know when he goes in hospital if he's coming home"* (Abi, HA).

Many of the parents recognised that the journey had an inevitable end. Josie (HA) admitted *"we know what's coming"*. Banu (HU) explained *"what will be will be. We know what's going to happen"* and John (HU) said *"something will happen. It will and there's no way around it. Which, unfortunately, is just part of what goes on"*. However, acknowledging the fact that their child would die and understanding what the end would be like, were very different concepts for parents as Julie explained (HU) *"you can't imagine what it's going to be like at all"*. Abi's initial denial was evident in her words:

"I don't understand it, and I don't exactly know what happens at the end. It's something that, we don't go there. But I know the time is coming that I've got to go there" (Abi, HA).

As in the previous theme parents often used figurative expressions to identify their situation. Consistent with the idea that life for some of them was like a war zone, Katie (HU) explained the unpredictability of life with a child with a life-limiting condition and said *"sometimes times are hard and the pendulum doesn't swing quite so fast, and sometimes it's all round the corner, we are sat there, a ticking time bomb effectively"*. Her words also suggested that life with a child with a life-limiting condition was time-dependent. Sometimes life appeared to be slow, possibly more manageable, whilst at other times something happens, goal posts are moved and parents are faced with making new decisions or changes in their lives. Using the example of both of her sons' experiences of participation in paralympic football, Sharon highlighted both the unpredictability and the speed of change for a child with a life-limiting condition:

"There will be a team there one weekend and the next, four weeks later you will say 'where's Freddie who played in goal'? and he will be dead. It's as sharp as that, we may have no warning what so ever" (Sharon, HU).

Like many parents Larai (N-HU) explained *"we don't know how long she's going to be here for"*. Sharon continued to express the difficulty for parents of *"not knowing"* the timing of the end, but also alluded to the fact that living with uncertainty was also difficult for her sons who have life-limiting conditions:

"I know it will come, but the thing for us is we have no idea whether it will be next week, or in a decade, and that's actually really quite hard too for my boys, well it's all hard to live with" (Sharon, HU).

Abi's (HA) situation was similar, but whilst her son Simon had dreams for the future Abi understood the reality, *"he'll say, when I grow up I want to do this, or when I grow up I want one of these cars, you know what I mean, but you think, well, that's not going to happen"*.

The nature of the illness meant that in many cases doctors were unable to give parents clear guidance in terms of timing. Charlie (HU) said *"I really don't know, the lifespan of Niamh, the doctors don't know"*. Doreen concurred with this view for her son Luke:

"Well because of his type of tumour, we don't really know what sort of happens with them in the end. So they couldn't give me any answers because they don't know what happens. He [doctor] said he could out live you, but he might not, so they just, they don't know what is going to happen with him, so that is their answer I think" (Doreen, HU).

James (HU) explained how *"you're given a diagnosis, but nobody actually knows"*. Edna (N-HU) described her journey as *"it's like going into a tunnel but you don't know how long the tunnel is until you're half way through it"*. Abi (HA) sensed that she was nearing the end of her journey as *"time is running out. That's the way you feel. That's what I feel"*. A few parents expressed their particular anxiety about not being with their child at the end. Pete (HA) became very distressed during his interview when he admitted *"it's something that bothered me right at the start, was Conor facing death on his own"*. Abi's (HA) concerns were clear *"I'm worried that when the time comes I won't be there, and I couldn't forgive myself"*.

A few parents had some expectations of time because of the type of terminology they had heard used. Life-limited for Abi (HA) meant that for her son Simon *"he's not going to live, until he's an adult basically"* whilst Ria (HU) believed that *"for me personally, this will be a near on twenty year journey"*. However, Laura's words, which met with consensus in one focus group, demonstrated that terminology like life-limiting did not give any clear definition of time frames:

"You do associate terminal with somebody that is imminently palliative, dying, whereas life-limiting, it could be, you know, something could go tits up in 6 months' time, or two years' time, but actually they might make it into their teens or whatever, they are just, they are not going to live as long as you would expect a child with no issues to live. So it's kind of open, it's not like, dead, dead close" (Laura, HU).

Amy (HU) believed that improved medical technology and more intervention meant that for her *"my journey's going to be a lot longer than anticipated at the beginning"*. For others like Pauline, David and Ruth the end of the journey was far in the distance. Pauline (N-HU) recognised that her son would not *"live to a grand old age of eighty"*, whilst David (N-HU) recognised that his daughter Lucy was *"not going to be here forever"* and he said *"we don't look far ahead and think, oh yeah Lucy's only got these many years left"*. For Ruth (HA) *"the future is kind of, it's something that is away"*. Emma's words described why discounting the inevitable was a necessary action,

"It's something that you know you've got to face sometime but, if you dwell on it, you would just . . . go into a black hole I think and never come out again" (Emma, HU).

For Katie (HU) there was a positive decision to avoid thinking too far ahead *"because you can't go there, you don't know it's there, you can go out of your mind, and all the rest of the stuff takes over"*. Because so much of their lives was governed by time such as, routines, schedules, lost time and unknown prognosis, there was a strong sense that it was important to ensure that every day counted. Like Josie (HA) many parents explained *"we are just trying to live each day, not knowing what is around the corner"*. Some parents like Katie and Sharon managed this well and had an attitude of *"live for today"*, trying to not worry about the future:

"I got Paul's diagnosis, and I sort of went, you know, life's too short, and this is proof, what am I doing, so no, no, we will deal with that when it hits, we will deal"

with that when it hits, because that's the time to deal with it. I don't want to live my life thinking that, you know, it's going to happen. It will happen, I know that, but I would much rather spend my time and energy on now, than worrying about what might happen. And what might not" (Katie, HU).

Sharon (HU) explained her attitude as *"you know, today is today, we can live today and worry about it tomorrow"*. Whilst recognising that time was precious because it was limited, parents' focus for themselves, their child with a life-limiting condition and their families was about enjoying life and about making sure that every day was a 'good' day. Abi (HA) said *"I know the inevitable, much as I know it, I'm never going to be prepared for it, never, but I also, you know, he's got to have his quality of life, that's the most important thing to me"*. Verity's (HA) view was similar to Abi's saying *"it's about the quality of life basically, so although we don't know what's around the corner, for us it's about making sure Jess is happy now"*. In the context that Stuart recognised his son Sam would inevitably die young, and not wanting to wish his life away or for him to suffer, Stuart explained how he assessed the value of each day:

"I will be happy if he would die quicker, but we know how it looks like. So what we can do just to make his life the best we can do. And every day we wake up and Sam wake up, and he smiles, and we just say, you had a good day yesterday (Stuart, HU).

Like David (N-HU) many parents were determined to be positive and manage the unpredictability as best they could, *"with the life-limiting thing, we just understand that you know, she's not going to be here forever, but we don't know when she will go really, and we just hope for the best all the time really"*. However, there were a few parents like Felicity whose feelings were more ambiguous. Despite the sense of frustration, Felicity's desire was to try to ensure she had more time with her daughter:

"It's fine, it's bloody not fine – but it will be fine, do you know what I mean, so sometimes you do have to get off the roller coaster, and how you get off I don't know, but sometimes you can make it slow down a little bit, just so it's not going quite so fast" (Felicity, HA).

Whatever perception parents held of their child's life there was a strong sense of anxiety about the new challenges they would face as they moved forward into the future. Caitlin

(N-HU) said *“there’s a dread always around the corner,.....you never think, ‘oh that’s it now. Free run’There’s always something to be dreading, or seem to be worrying about”*.

6.1.2 Fear for the future

Across both phases of the study there were thirteen children above the age of sixteen years. For those parents, rather than concentrating on the inevitability of death, many were anxious about the potential future transition as young people from children’s services to adult services. The view held by parents was that the choice and availability of services in the adult field was even more limited than in children’s services, Caitlin (N-HU) commented *“I’ve got friends who are in the situation above me, and as soon as they hit eighteen it’s all ended”*. In terms of respite support Bernie (N-HU) believed that she *“was going to have nothing when her son reached nineteen”*. The association that transition had with loss of familiar services and carers was defined clearly in the words of Caitlin (N-HU), *“all your staff that you’ve had all your life, it’s all gone. So, you know, it’s horrendous. That’s going to be another big bereavement isn’t it?”* Jane (HU) described a future in adult services for her daughter as *“stuffed”* because *“there’s nothing in place for, well for all spectrums really, but especially severe complex children, because of their health and nursing needs”*. Some parents were worried about what they perceived as a greater battle accessing services in the adult sector. Jane’s view was one where she believed:

“I know there’s nothing for disabled adults, nothing. They are shutting everything down. I know people that work in the adult services, it is just a thing, and it’s a great big fight” (Jane, HU).

For a few parents with personal experience of their child having gone through transition, their evaluation of the process was poor. Despite *“two years of planning”* Charlie (HU) explained how there was a *“five month gap when we had no respite”* after accessing adult services. She described transition as a process where *“there seems to be an awful lot of talk, a hell of a lot of talk and planning, and then when it comes to it... you feel like you’ve entered a black hole over it”*. Unfortunately, this was a common experience amongst the parents with their child’s transition to adult services. Julie (HU) described transition as *“a long, long, sort of struggle, with very poor communication”* whilst Jill (HU) described it as *“a nightmare”*. Penny (HU) described how with her daughter Tanya it was *“a classic example of slipping through the net”* because *“school thought Social Services were helping me, they thought school were helping me, and in the end I did every single thing myself”*. James (HU)

described the lack of choice of adult services available for respite for his son, *"I sort of feel that I'd made choices, not because I, you know, where I've chose, not where I feel is ideal, it's just the best that's on offer"*.

For Ruth (HA) the fear of transition to adult services was about it happening too fast, *"it comes round very quickly doesn't it, and I know that, you know, I'll be getting people saying, 'What about this?, What about that?' and I'll go into my hibernation again"*. Although Abi (HA) was trying to live each day and not worry about the future her words demonstrated her anxiety, *"I live a day at a time, but it's quite frightening, when they get to 19, everything stops"*. Fran (HU) clearly described her anxiety *"at sixteen I know it will come, I haven't even thought about it yet, because I know it will come like a steam roller towards me, and I will have to kind of get out the way"*.

For a few parents who acknowledged getting older themselves, the overriding fear for the future was linked to their anxieties about who would care for their child. Pauline (N-HU), an older mother, said *"I worry about not being around forever for Fred"*. Edna (N-HU) said *"my anxiety for Thomas is that he will live so long that we will be unable to care for him, that he could potentially live a normal life expectancy, how would we then manage his care"*. Edna (N-HU) continued to express her concerns regarding this as to the effect on Thomas' sibling, *"my fear is, will Janet take this on, you know, she will grow up, and that will affect her life overwhelmingly"*.

Anxieties for the future were not only linked to the transition into adulthood but they were also present at other stages of development. Pauline (N-HU) recounted her anxieties at the time when her son Fred was able to go to preschool, remembering *"but at three he was supposed to start school three days a week, so it was like, 'oh my god, they are going to take my baby off me' "*. David, whose daughter was at preschool, expressed his concerns about Lucy going to school full time:

"...because she's going to have to end up going to school full time, do we send her school full time? Or are we just going to keep her at home, and home school her, because, but we don't know how that works, as in like, if they can force us to go or we say 'no her health means that she can't go' " (David, N-HU).

Linda described different anxieties for the future of her two teenage sons:

"Bill has got the potential to go to University, to live independently. I hold on to all that. But I know that it is going to be really hard to do..... But equally for Ben he hasn't got that potential, and I worry about where he's going to end up (Linda, HU).

Sharon's son was already at university. She described her worries about the next step for him:

"Rob is doing a four year degree, two years to go, but, I'm already thinking, then what is he going to do,who is going to employ him, that's going to be really, really difficult, even with, the best will in the world, that's a tall order" (Sharon, HU).

In summary, while the future is inevitable and unpredictable for all of us the thing that is different for parents of children with life-limiting conditions is the feeling that 'death' is close, even if there is no clear sense of how close. As parents of children with life-limiting conditions live day by day they are faced with many challenges and many uncertainties about the future. To survive and move forward parents focus on the here and now, *"making every day count"*. This is summed up by Katie who said:

"if you worry about what happened in the past, that's where your focus is, and you don't do things that you need to now, and if you're in the future, you're just anxious all the time, worried all the time, on what may be, and you're more likely to make bad things happen if you focus on them, so we don't want to go there" (Katie, HU).

However, as parents coped with the challenge of taking one day at a time they recognised that with each new day with a child with a life-limiting condition there was the potential for new and difficult challenges. Times of change, such as starting school for a child with a life-limiting condition, caused increased and heightened anxiety for some parents. The unpredictability of the nature of a child's condition meant that changes could happen very quickly. The transition to adulthood was a particular stressor and caused many anxieties for some parents. For those parents who had experience of transition into specific adult services, the outcome was poor. In the next core category the complexities that transition from childhood to adulthood presented for this generation of children with life-limiting conditions are considered in more detail.

6.2 Uncharted Waters

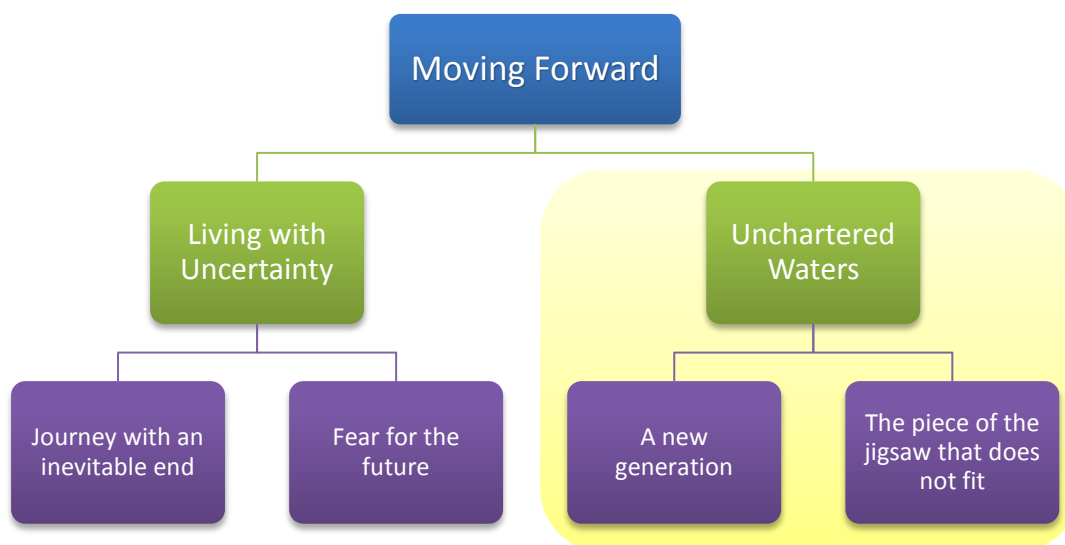


Figure 6.2 Theme Three – Moving Forward: Core category – Uncharted Waters

Parents described how, despite having a life-limiting condition, many of their children were surviving longer and outliving parental expectations. This core category presents findings which concentrates on this generation of children with life-limiting conditions who have reached their teenage years and whose condition trajectory has extended beyond childhood, and is moving towards adulthood. This meant that many parents were faced with caring for a young person whose future would mean moving into adult services. This core category depicts the unpreparedness of both parents and service providers for this new generation of young people. As well as coping with their son or daughter's inevitable decline in health, parents had to leave the familiarity of children's services, and where they felt they belonged, and start to access adult services.

Some parents of children with life-limiting conditions perceived that transition to adult services was a misnomer as although chronologically an adult, their son or daughter would always developmentally remain a child. Parents also believed that choice of service provision was more limited for adults. The perception was that the challenges parents and their son or daughter would face would be more difficult and ultimately life would be more of a struggle than it was now. Many parents perceived that the outcome of transition

to adult services was a transition to something worse. For those parents who accessed Woodlands, whilst everything else around them was changing and they were having to access adult services for other provision, there was some reprieve in the process of transition and a little security in knowing that their son or daughter could continue to access respite at the hospice until the age of thirty years old. However, for many other parents the view held was that everything stopped when their child reached 19 years.

There was also a group of young people who accessed the hospice for respite services whose experiences were perceived by their parents as being different to the typical hospice population. They were primarily young men with Duchenne's muscular dystrophy who despite being physically dependent were cognitively able. Parents' views were that because of their cognitive ability and mental capacity these young men had different needs from other children and young people at the hospice who were not cognitively able. They were *"the piece of the jigsaw that didn't quite fit"* at the hospice. For one parent the view was that the hospice was not the right place to go for respite for this group of young men.

6.2.1 A new generation

There was a strong consensus from many of the parents that their children were surviving longer than they as parents had anticipated, or that they had been led to believe when their child was born. Penny (HU) explained how *"if they said you had life-limiting you thought they were going to, their life was going to end in 6 months. But now nobody can say can that"*. Mona (HU) explained how in her situation doctors had been using the term *"life-limiting condition for twenty plus years"*. Julie (HU) described how her children were only *"expected to live until they were fourteen or fifteen"* and Fran (HU) commented how her daughter at the age of twelve had *"exceeded all [doctors'] expectations"*. Constant caring for some parents, like John, meant they were often not aware of time:

"I didn't think we'd see sixteen without a doubt. I didn't see him carrying on this long. Crikey.you time just ticks on, and you think 'Oh he's ten', and the next minute he's thirteen and now he's sixteen" (John, HU).

Fran believed that improved survival in children with life-limiting conditions was because of increasing technology and expert parental care:

"...with our children, if there was no medical intervention, no tube feeding, no physiotherapy, percussion and so on, they would soon be needing palliative care. They wouldn't last long. So it's only because of all the things we do as parents, and all the stuff that's done every day, that they keep going really" (Fran, HU).

The result was, as Mona (HU) described, *"a whole generation who've survived childhood"*. However, the strain of caring for so long in some parents was evident, Sharon (HU) described the effect of looking after her two sons, *"we've been looking after the boys for just over seventeen years, it drives you up the blinking wall"*. For other parents this meant the need to constantly change. Caitlin described her situation where an extension had been built at home and now her son Peter had outgrown it:

"Peter was 3 when I had that extension, you know, and I'm thinking now I could do with three times the size of that, but you can't afford to extend your houses and things" (Caitlin, N-HU).

As these young people got older the idea of transitioning into adult services became more of a reality. For many parents this became a huge tension. Although Bernie's (N-HU) son, Joshua, was eighteen, developmentally she explained *"I would put him at a three year old, although he's eighteen, three because of the things that he does"*. The view that there was a discrepancy between chronological age and development with these young people was evident with other parents. Caitlin (N-HU) commented *"some of the children that I've seen at eighteen, they are like 10 year olds, so I just think it's a bit silly"*. Amy (HU) commented *"these children, are always going to be like babies"*. The overriding view was that there was a sense that transitioning to adult services was pointless. Referring to the children's community respite she received Pauline (N-HU) said *"the day he turns 18 they can't come in anymore, so that's what the rules of that service are, and I think it's crazy, crazy"*. Charlie (HU) commented, *"why does she have to leave school? Niamh is not like a eighteen year old, she's, she could stay doing the primary section forever sort of thing"*. Caitlin's (N-HU) words typify the general feeling held by many of the parents that their children would never be adults, she explained *"it's like having a baby of six months for the rest of your life"*. Fran (HU) explained *"the only thing that works against them is age"*, and her view was that *"my child will never be an adult, she will always be three"*.

Other parents shared similar views, Bernie (N-HU) described how her eighteen year old son continued to like to read picture books and Suze's (HU) view in regards to her twenty

year old son was *"it's a misnomer calling it adult services, when he still wants to play with sand and water"*. As Fran (HU) explained the facts for their children were *"it's not just the physical age, it's their learning age. Because you could be seventy and still three"*. The view was that as these young people get older they do not become more independent, their care needs remain and often become more intense. Pauline said:

"Why do you have to have adult and child services, because if you've got a child with all these needs they don't change when they get to adult, they don't from 18 change in any way, whatever, they are just bigger, but the service you are doing, you're dressing them, lifting them, putting them into another chair. It's exactly the same, whether they are this big or that big" (Pauline, N-HU)

As described previously choice of respite services was limited. Some parents were anxious about adult services being unable to meet the needs of their son or daughter. Bernie's (N-HU) fear for her son was that transition meant he would be placed in an adult care facility which would not provide for his needs and she believed that he would *"feel out of place"*. She described her perception of adult respite, and said:

"My fear is that he would end up with, somewhere what I call, the granny syndrome, where they are all sat in a room with a big empty space in the middle and just pinned down" (Bernie, N-HU).

Like Bernie, Penny (HU) also believed Tanya's needs would not be met, she explained, *"they will have the snooker on the telly and Tanya wants, she wants Mr. Tumble. That's just not gonna work is it?"* The challenge for this new generation of young people with life-limiting conditions was that they did not appear to *"fit into any box"* (Ruth, HA) and adult services had little or no experience in meeting their needs. Mona (HU) said *"I remember when we were going through transition, everybody we met in the adults was saying, 'Oh, he's unique, he's unique, we've not come across somebody like this'"*. Penny described the experience of her daughter when she had tried an adult day care facility:

"We went in, and there's men sitting there, that were about 70, and there's my little Tanya, and they're going, they come up to her and they're going 'Eerrr errrr' to Tanya, and I went 'Ah'!!!!" (Penny, HU).

Penny's description continued, her words reflected her emotions, her concerns and the lack of choice that she perceived:

"The trouble is, when you reach adulthood at eighteen, that's eighteen to whenever, and that's the sad bit, because, I looked at it, and that's when the reality sets in, I went home and I just cried all day. I thought I'd rather have her at home, than that. 18 to 30's, they should be with their own age group, talking about pop music, and not sitting there with old men, putting their hands on their knee, and I didn't want that for Tanya" (Penny, HU).

Parents also recognised that as life for their young person was extended there was also deterioration in the overall health of their child. Linda (HU) explained how difficult it was for her and her husband to watch this with her two sons, *"you're grieving because you know the outcome, we both know what's going to happen, initially you see your child thrive, and then be pulled away, back, it upsets us, the loss of potential"*. Despite his son being sixteen John (HU) believed that *"there can only be deterioration, there will be no progress or anything like that"*.

Linda's words reflected the sense of relief in knowing that, if required, respite continued until the age of 30 years:

"Now it goes up to 30. And from my point of view, that provides me with a safety blanket and a bit of reassurance, because often with that transition from children to adults you completely fall off the cliff. And I know how crap it is for adult services, and you just know, actually, if it is going to be awful, at the end of the day I do know that Woodlands will still be there" (Linda, HU).

There were however three parents from the hospice user group who, although they were happy with the idea that respite could be accessed at the hospice until the age of thirty, held the view that the current scope of delivery by the hospice was too wide. Suze said:

"I think places like Woodlands have got too big, they are trying to deal with too many complexities of people. If they were smaller units, and more smaller units, dealing with children like Nick, or children like yours and yours, or whatever you know, then it would be much better, than somebody trying to deal with the whole lot, from 0 to 25 or 30 – it's too cumbersome" (Suze, HU).

Jill's (HU) words demonstrated the overall consensus from parents of older young people that there needed to be some review or change to the existing model of respite care delivered by the hospice. She said *"I think the model needs changing,.....because needs have changed so much that, the original idea needs splitting up into different categories now"*.

She suggested a separate space for older young people, *“they [Woodlands] should be aiming for a young people’s unit, separate to a children’s unit where it is run as two separate things, side by side”*. Whilst Julie’s words reflect obvious relief in being able to access hospice services up to 30 years like many other parents she recognised that age was not an accurate reflection of needs and that the future need for respite for young adults with life-limiting conditions was age-dependent:

“Siobhan is 25 now, she’s only got 5 years left, so she may not live for more than 5 years, but I kind of think when she gets to 30, I kind of lose all this, that’s really, it’s, it’s great that she’s managed to live that long, but at the same time, it’s kind of, there’s kind of an end point to that. To all this, and in a sense she’s not going to be any different when she’s 31 than when she’s 30” (Julie, HU).

The notion of a separate space for older young people was also evident from the parents of the group of young people whose condition meant that although physically disabled and continuing to deteriorate they were cognitively more able. The next section will detail the additional challenges that parents perceived these young people faced as they got older.

6.2.2 The piece of the jigsaw that does not fit

This subcategory is specific to parents of young people who were cognitively able (primarily Duchenne’s muscular dystrophy (DMD)) and who were using the hospice for respite because there was nothing else available, as Mona (HU) said *“it is the only place they can go”*.

In phase one this accounted for eight of the twenty four children identified in the sample and six parents, and one parent and child in the hospice aware group. For this generation of young men life was more complicated and the future was more uncertain as Ann explained:

“Jarryd is kind of sandwiched between children that have always been in special needs and have the same physical needs as him, but are mentally a lot more immature, because they have always had the molly coddling of a special needs school. Or peers at high school, they are going out with their girlfriends, this that and the other, stuff that he is not doing, and he is kind of there, smack bang in the middle. He has the emotions of both, but he hasn’t really got any mates that are on the same sort of wavelength” (Ann, HU).

Parents explained how although these young men were physically disabled *“he can’t move anything else of his own”* (Sharon, HU), they had normal cognitive function *“mentally he’s absolutely fine”* (Ann, HU). Sharon’s explanation was that *“essentially my boys are leading normal lives, if you like, but with all the medical back up”*. It was clear that this group of parents perceived their young people as different from many of the other children with life-limiting conditions at the hospice. Whilst the value of the hospice and the recognition and appreciation of the services it offered to many families was evident, with reference to children with life-limiting conditions with little cognitive function, Sharon stated:

“for these children it sounds like it’s absolutely right, and I, but I think that’s because they’ve had decades of experience of providing this support for those sort of children, you know, with those complex needs and parents that are completely knackered and need somewhere that can manage pegs and ventilators without thinking ‘Oh, are they going to do it right?’ .. but, so I think that’s what I think that’s its essence, because that’s its [hospice] roots” (Sharon, HU).

Parents described how the teenagers and young adults were using the hospice as a social hub to meet with other young people like themselves. However, Sharon (HU) was *“slightly appalled”* that the hospice was the only option for a *“social hub”* for young men like her two sons to meet with other DMD boys. Sharon’s opinion was that the hospice was possibly not the *“right place”* and she expressed her concerns that for her two sons: *“I was worried, thinking, do these boys fit? What are they going to feel being put in this place [the hospice] with these children with highly complex needs?”* Similar to Sharon’s view, the general perception amongst this group of parents was that their children had different needs from other children at the hospice and that therefore they needed people with a different skill set looking after them, in addition to a different model of delivery. Both Linda and Ann agreed with this idea, Linda (HU) said *“I think the skill mix as a professional, or whatever within the hospice, is totally different for a young adult, than it is for a child”*. Ann suggested that professionals’ skills were used differently:

“..... there might be some staff that would be better with our lads, that are more kind of outgoing, bubbly, and they might have more caring staff, not that our young people don’t need caring people, (lots laughing) but would be more, their tone of voice, you now for people who work more on senses, are quite happy to sit and read stories” (Ann, HU).

Whilst Sharon's words implied that professionals with a different skill set other than being children's nurses was needed to adequately meet the needs of these young people:

"the hospice is not keeping up with this generation, the hospice needs to catch up with the fact that these boys, they are living, and may live for a long time, they are not winding down and that as these Duchenne boys have lived longer and it is more Duchenne isn't it, than anything else, children's nurses, kind of haven't caught up really" (Sharon, HU).

There was also a clear sense that despite their cognitive ability, many of the older young people were still being treated as children by the hospice staff. Sharon's frustrations were evident as she relayed the questions that were asked when she brought her oldest son to the hospice for a short break:

"...there's somebody saying to me, is he allowed a drink, 'Well he's 18, it doesn't matter two hoots what I say, he can have a drink' Is he allowed to swim? What time does he want his breakfast on Sunday?, and I'm just thinking, 'Go away, ask him on Sunday, don't ask me' " (Sharon, HU).

Instead parents wanted their young people to be encouraged to take more responsibility for their care and be more involved in decision making. Sharon's (HU) view for her sons was that they needed to *"be in charge of their own care"*. Whilst Linda (HU) recognised the potential for difference between her two sons, she wanted to encourage some independence in them:

"They may not necessarily get there, but if they start to take some control of what happens to them, you know, I know both of them are going to need 24 hour care, but I know Bill probably, should be able to manage that himself, but Ben no way, but, but just kind of equipping them to be able to take on some level of responsibility is important" (Linda, HU).

Other parents like Ann and Ria wanted to see more planned activities and opportunities for their sons to meet up. Ann (HU) explained that *"for this kind of generation for them to be able to organize say twice a month, they all get together"* and Ria (HU) said *"I was hoping they could create their own entertainment and plan a day for themselves"*. However the reality was that young people were often at the hospice for respite when there were no other cognitively able young people present. Ann explained that for her son Jarryd *"it's very rare he's ever been here and there's been another child he can even talk to"*. Linda (HU) was relieved that her sons had *"each other"* when they came to the hospice because *"sometimes they've gone and perhaps there's more complex children that they can't kind of*

talk to and socialise with". Despite the potential for socialisation, being at the hospice was a lonely experience and Doreen (HU) described how her son Luke would often telephone her and ask "can you come and pick me up I'm bored". Ria (HU) concurred with this view and said "since Will got to probably about the age of twelve, he finds there is absolutely nothing to do" at the hospice. Ann's explanation offered some insight to this:

"It seems almost like Woodlands is more catered to kind of sensory needs, you know, for children, like the sensory room is amazing, you know, and I do find, because I have got some friends whose children come here, and do have like, severe cerebral palsy, and stuff, and they gain so much out of it, that you can't possibly do at home. But for the children that are more able bodied, mentally able, I find that there is more of a lack of stuff for them" (Ann, HU).

The nature of the hospice as a professional establishment meant that the hospice was required to adhere to certain policies and procedures to safeguard the care of children, young people and young adults in their care. Unfortunately this meant that some parents perceived the model of care delivery as restrictive. Doreen explained the instructions that had been given to her son:

"He's had a talk about restricted places that he can go now, he can't mix with the younger ones without a staff member, he can't go wandering off, he can't be talking to members of staff at night, because he wakes up during the night, and just comes out his room, and he will be talking at the nurse's bay. He can't do that no more" (Doreen, HU).

The sense of restriction continued as Ann (HU) explained that *"Jarryd's not allowed on any of the computer games that are over sixteenHe's not allowed to watch certain films and stuff, so to him, the things he does at home, he's not allowed to do here. So it's, what's the point in coming?"* Both Linda and Abi agreed with this view, Linda (HU) said *"...Bill and Ben can't do the things, because there's so little they can do now, the things they can do, they're almost not allowed to do at Woodlands because of their age".* Abi (HA) explained how *"things he's allowed to do at home, he's not allowed to do here".* The feeling that the hospice was not providing for the needs of this group of young people continued as Sharon (HU) explained *"they go to the hospice but it becomes a place where they don't do stuff. And that's what's got backwards, where actually they're not living their lives".*

Because of this Sharon described the hospice as a *“holding place”* where rather than a place for living and enjoying life boys like her sons were standing still. She suggested that *“it was the hospice world stretched too far”*. Instead Sharon suggested a respite model of delivery that was akin to a *“hotel type facility”*. Mona (HU) suggested a place with a *“youth club kind of support”*, whilst Abi (HA) wanted Woodlands to do *“day care in various locations”*. The notion that these young men had different needs which warranted a separate space was evident across the group of seven parents. Sharon (HU) summarised and explained that Woodlands should *“separate the complex needs from those that haven’t got complex”* (Sharon, HU).

6.3 Conclusion

This chapter has described the findings of the study which have provided insight into the third theme identified as *“Moving Forward”*. For parents living with a child with a life-limiting condition poses many challenges. Knowing that all the while they are moving forward towards the inevitability of end of life for their child, parents’ focus was on achieving a good quality of life experience. Whilst many parents agreed that their child’s needs would never match those of adults, because their children were living longer, their age meant that many parents had to overcome their anxieties regarding the challenge of transition to adult services. In caring for young people to the age of thirty years, the hospice provided some reprieve for some parents. For others the choice of services available was very limited.

There was also group of young people with life-limiting conditions, who although cognitively mature accessed the hospice for respite because there was no other service available. For this group the current model of care delivery did not meet their needs because despite having a life-limiting condition they were *“living, and may live for a long time, and are not winding down”* (Sharon, HU). For various reasons the view held by the majority of parents was that the hospice was not the right place for these young people to access for respite services.

In the next chapter the findings of the study and the three themes identified, Coming ‘Home’, This is Living Now, and Moving Forward are explored in the context of literature reviewed pertaining to the developed grounded theory.

Chapter 7 Discussion and Analysis

"Where you belong is where you are safe, and where you are safe is where you belong". Ignatieff (1994:25).

In the previous three findings chapters three broad themes were presented, Coming 'Home', This is Living Now and Moving Forward. These three themes reflected the experiences of the three groups of participants: hospice users, hospice aware and non-hospice users. The purpose of this chapter is to draw together the three themes and present a theoretical understanding of the parent's search for a place, other than their actual home, which offered some respite from the continual caring of their child with a life-limiting condition. This was a place where they felt they belonged and a place with which they developed a bond. Using the concepts developed from the grounded theory analysis of the findings, the discussion and synthesis presented will draw on the current literature focusing specifically on notions of place bonding, attachment and belongingness. The contribution to new knowledge for paediatric palliative and hospice care will be considered.

7.1 Introduction to the Concept of Place and Relationship

The growing interest in the phenomenon of place is demonstrated by the increase in the numbers of studies published amongst the various disciplines including human geography (Relph, 1976; Seamon 1979; Tuan, 1980), environmental sociology (Stokols and Shumaker, 1981), environmental psychology (Proshansky et al., 1983), recreational and leisure studies (Williams et al., 1992; Hammitt et al. 2004) urban planning and conservation psychology (Bott et al., 2003). Various key concepts which explore the relationship between place and people have been described in the literature; place attachment (Low and Altman, 1992; Scannell and Gifford, 2010), place identity (Proshansky et al, 1983; Twigger-Ross and Uzzell, 1996), place dependence (Stokols and Shumaker, 1981); place bonding (Hammitt et al. 2006) and place belongingness (Baumeister and Leary, 1995; Hagerty et al, 1992). Whilst all of these concepts have bearing on an individual's relationship with place, there is confusion in the literature amongst the disciplines as to how the various constructs link together. Described as

attempting to put together different pieces of a broken jigsaw puzzle (Lewicka, 2011:208), the mere fact that many authors come from different theoretical backgrounds such as sociology and psychology, means that relationships and links between the various place-related concepts are not clear and often confusing.

It is not the intention within this thesis to debate the various philosophical approaches, methodologies or frameworks identified, nonetheless, the discussion presented below will draw on the various viewpoints to highlight the concepts that have emerged from the grounded theory analysis of the findings. This introduction identifies some of the overlap that exists conceptually amongst the various concepts and terms used reflecting the complexities and nuances of the theoretical views associated with the notion of place and relationship.

7.1.1 Place attachment

Place attachment is described as the affective bonds which develop between individuals and places (Low and Altman, 1992; Giuliana, 2003; Twigger-Ross and Uzzell, 1996). The first reference in the literature to the notion that affective bonds are formed with places is found in a study by Fried (1963) which explored the psychological effects from a forced relocation of a suburban community in Boston during the move and again two years after the move. Results showed the effect of the relocation in many individuals was similar to the grief and loss experienced after the death of a loved one. Fried believed the move had broken the sense of community experienced by individuals and had impacted on their identity with place.

As the awareness of the emotional attachment that individuals have with various places grew the idea of place attachment and its various definitions emerged. The interest in human experience of place has been particularly noticeable amongst key humanistic geographers and phenomenologists (Relph, 1976; Seamon, 1979; Tuan, 1980). Both Relph (1976) and Tuan (1974) postulated that the development of a bond with a meaningful place was a fundamental human need and described a strong affection for a particular place as 'topophilia'. Relph (1976:49) alluded to both the notions of place identity and place belongingness by using the term 'insideness' to suggest that the stronger the sense of belonging an individual experienced in a place the more they identified with that place.

Both Tuan (1974) and Relph (1985) suggested that the intensity of the affective bond varied from immediate delight to long-lasting rooted attachment.

Various concepts, processes and models involved in person-place bonding have been proposed demonstrating the diversity that exists even within disciplines (Twigger-Ross and Uzzell, 1996; Giuliana, 2003; Low and Altman, 1992). The most common concepts mentioned are those of place identity and place dependence. There are two ways in which place and identity have been described in the literature; the first described as place identification refers to a person's expressed identification with a place, that is, their membership to a group of people defined by location (Twigger-Ross and Uzzell, 1996:205). The second is described as place identity. Place identity, whilst similar to place attachment is concerned with the idea of a sense of belonging and argues that the bonds developed between place and individuals in turn influence an individual's self-identity (Proshansky, 1978; Proshansky et al., 1983). Unlike Proshansky (1978) who proposed that place identity was a separate part of identity concerned with place, Twigger-Ross and Uzzell (1996:206) suggested that *"all aspects of identity have place related implications"*. Whilst Twigger-Ross' study explored the relationship between identity and an individual's place of residence it highlighted the links between identity and place which led to further exploration of the notion of place identity and locations other than one's dwelling place.

Whilst concurring with the identified factors of how individuals use dwelling places to construct self-identity (Twigger-Ross and Uzzell, 1996), Gustafson (2001) demonstrated that these factors could be further elaborated to explore the meaning that individuals attribute to places more generally. In his framework Gustafson (2001) described how the meaning of place is associated with personal identity, the perceived characteristics of other individuals in the place and the physical environment of the place. Integral in Gustafson's (2001) framework is the notion of dependence on others and the environment. In other literature the concept of place dependence is described as the strength of association that exists between an individual and a place (Stokols and Shumaker, 1981; Hammitt et al. 2006). This is similar to the idea of place belongingness, described as an individual's deep attachment to a place to the extent they perceive themselves as being an integral part of a place (Hagerty et al, 1992; Baumeister and Leary, 1995). The need to belong has been shown to be a fundamental human motivation that

has a powerful influence on cognitive processes, emotional patterns, behavioural responses and health and well-being (Maslow, 1954; Baumeister and Leary 1995).

Within the literature, personal connections to place in terms of dependence and belongingness tends to focus on the idea of one's dwelling place. The complexities of the notion of 'home' and our attachment as individuals to it are demonstrated by the multiple meanings associated with the language to describe 'home'. Much of the early work on the notion of home literally meant one's dwelling place (Relph, 1976; Seamon 1979; Tuan 1974). 'Home', identified as an individual's residential dwelling place was used as an example of a place where an individual could sleep without fear or threat, be completely free to feel themselves and experience rest and restoration (Seamon, 1979). Home has also been described as a way of being-in-the-world (Heidegger 1971) and therefore influential in the 'formation of our identity, the dwelling place of being' (Relph, 1976:39). Building on Relph's work, Seamon (1979:15) suggested that if individuals developed a relationship with a place they would experience a sense of 'at homeness' with a place. In his work Seamon (1979) identified five concepts as pre-requisites for ensuring that an individual experienced this sense of 'at homeness': rootedness, regeneration, at-easeness, warmth and appropriation. Over time, Seamon (1979) suggested that if a person developed an intimate knowledge of a place the extent of the emotional attachment and the feelings created in turn dictate the sense of rootedness an individual has in a place.

In order to truly reflect the notion of the meaning of and relationship to place for individuals a holistic view of the entire range of experiences must be considered (Relph, 1976). Research has suggested that people deprived of belongingness experience diminished self-esteem, decreased well-being, anxiety and depression (Sargent et al., 2002; Baumeister and Leary, 1995). Whilst the literature on place attachment has concentrated mainly on positive experiences of place, the need to belong and the process of forming affective bonds with places, there is much less evidence on the impact of negative experiences. Whilst 'insideness' portrayed the image of intimacy and rootedness in a place, the idea of 'outsideness' paints a picture of alienation and strangeness (Relph, 1976). In his work on place identity Proshansky et al. (1983) acknowledged that place identity was influenced both by positive and negative emotions and thoughts. Tuan (1974) uses the term topophilia to describe a strong affection for a place and the term topophobia to describe an aversion to a place. The more a place is perceived as threatening, the less

belonging is felt and the more an individual experiences a sense of uprootedness (Godkin, 1980).

In summary it is apparent in much of the literature that theoretically addresses the concepts of place bonding and place attachment, the affective bonds that humans form to significant places in their lives is as a result of cognitive and affective processes (Stedman, 2003). Terms like place bonding and place attachment are often used interchangeably, and the complexities surrounding the concept of attachment to place are evident in the overlap between ideas such as, place dependence and belongingness. Much of the early work (Relph, 1976; Seamon, 1979) exploring the meaning of place and place experience concentrated on the image of the 'home' dwelling place. However, the meaning of place for people in other locations and the factors that affect their relationships with places outside of their family home has led to the view that many places other than the 'home' such as, leisure and recreational places, are important in people's lives and have meaning in their lifeworld (Gusatfson, 2001; Hammitt et al., 2006; Manzo, 2005).

7.2 Introduction to the Developed Theory

Place bonding in recreational studies has developed over the last twenty years (William et al., 1992; Jorgensen and Stedman, 2001; Hammitt et al., 2004; Oh et al., 2012). The first model identified in the literature to measure recreation place attachment was the two dimensional model developed by Williams et al. (1992) consisting of place identity and place dependence. Over the years several different dimensions have been added to this model, such as affective attachment (Jorgensen and Stedman, 2001) and social bonding (Kyle et al., 2004). It is the five dimensional model of place bonding devised by Hammitt et al. (2004, 2006) which is used as a theoretical basis for the discussion of the findings from this study. Although Hammitt et al.'s work (2004, 2006) considered the concept of bonding in a recreational environment, his dimensions have a strong resonance with the ways in which parents talked of their journey to the hospice.

Hammitt et al.'s model (2004, 2006) proposed that five dimensions, consisting of place familiarity, place identity, place dependence, place belongingness and place rootedness are necessary for an individual to experience a sense of place bonding. Using a multidimensional scale Hammitt et al. (2004, 2006) surveyed experienced trout anglers

(n=203) at the Chattooga River (USA) exploring their experience use history, measuring the five dimensions of bonding and their substitution choices if they could not fish at the river. As is the case with many studies in recreational settings (Williams et al, 1992; Jorgensen and Stedman, 2001; Oh et al., 2012), Hammitt et al.'s work focused on quantitative measurement and analysis of the concept of place bonding. Trout fishing is characterised by having users who repeatedly use the same locations; on average the anglers had fished on the Chattooga for fifteen years with an average of ten fishing trips in the last twelve months (Hammitt et al, 2004). Whilst Hammitt et al.'s study was not concerned with qualitatively exploring experiences it examined a large sample of anglers to investigate which dimensions of the proposed model provided the most valid and reliable assessment of the phenomenon of place bonding (Hammitt et al. 2004).

The **familiarity** dimension of place bonding referred to the anglers' positive memories, thoughts and images associated with the stream. **Place belongingness** was described as the affiliation and connectivity with the stream which resulted in the formation of communal bonds with the environment and other anglers at the stream. **Place identity** was concerned with how the place of the stream helped define self-identity among the individual anglers. The dimension of **place dependence** was associated with the potential of the stream to satisfy the needs and goals of the anglers and how that compared to other environments that might satisfy the same needs. Finally **place rootedness** referred to the sense of feeling so secure, comfortable and completely at home in the location that an individual angler had no desire to seek out another recreational place for angling (Hammitt et al, 2004, 2006).

7.2.1 Original contribution to knowledge - Place Bonding: journey towards a sense of rootedness in children's hospice care

My original contribution to knowledge is the exploration of how place bonding is at the heart of the search for a sense of rootedness for parents of children with life-limiting conditions. The theory developed provides an explanation and understanding of the conceptual journey that parents undergo as they grappled with their decision to seek help in the form of respite care. Whilst the theory presented is specifically applied to a hospice setting for those parents who had not yet used the hospice their cognitive journey was the

same. Whilst they were not at the point of progressing their need to search for something else, they did acknowledge their potential need for help in the future.

For most parents there is a natural bonding with their own home. However, the nature of having a child with a life-limiting condition meant that amongst all three user groups (N-HU, HA and HU) despite this deep sense of rootedness identified with their place of home, parents recognised their need or future need for help in caring for their child. As parents began to consider their options for help to care for their child their sense of rootedness at home became disrupted. The journey towards the hospice begins with a sense of uprootedness as parents begin to search for a place, other than their actual home, where both they and their child could experience the same sense of belonging that they felt at home. The ideas of Coming 'Home', This is Living Now and Moving Forward and the associated categories formed from the grounded theory analysis are explored in light of (Hammitt et al.'s, 2004, 2006) five dimensions of place bonding: place familiarity, place identity, place belongingness, place dependence and place rootedness.

An overview of the importance of finding a place that parents felt secure and safe to be able to leave their child is highlighted in place familiarity. Place identity is considered in both the positive and negative connotations associated with the identity of the hospice and the influence that this had on a parent's self-identity. The characteristics described by parents as fundamental to achieving a sense of belongingness in the hospice are detailed in place belonging. Rather than use the terminology place dependence within the developed theory the notion of place association will be used to depict the reliance that parents had with the hospice. Historically within nursing historically the idea of dependence has been used in resource measurement to depict the needs of patients balanced against the supply of staff to care for said patients. The notion of place association appeared to conceptually reflect more accurately the functionality of the hospice in providing quality care and therefore meeting the needs of the parents rather than the negative connotations that Stokols and Shumaker (1981) describe as being associated with the idea of nursing dependence. Finally the concept of rootedness portrays the sense that parents had finally found a place where they belonged and where they truly felt at 'home'.

The overall theory illustrated in the diagram below (Figure 7.1) represents the complexities of decision making and the interrelationships between the hospice in the centre and the five dimensions of bonding which surround it. The journey that parents are on with their child is not a straightforward process, the wave represents the troughs and peaks that parents described. The nature of life-limiting conditions meant that for some parents the speed of the journey was fast as their child's illness trajectory gave them only a short time to bond with the place. For other parents their journey took place over many years. The journey was also dictated by the age of the child. The theory considers how as parents moved forward with their lives and their child got older, they were faced with the prospect of transition into adult services. The consequences of this meant that once again parents would find themselves displaced from the place they felt they belonged and had become rooted in, the journey to search for a place in adult services would begin once again.

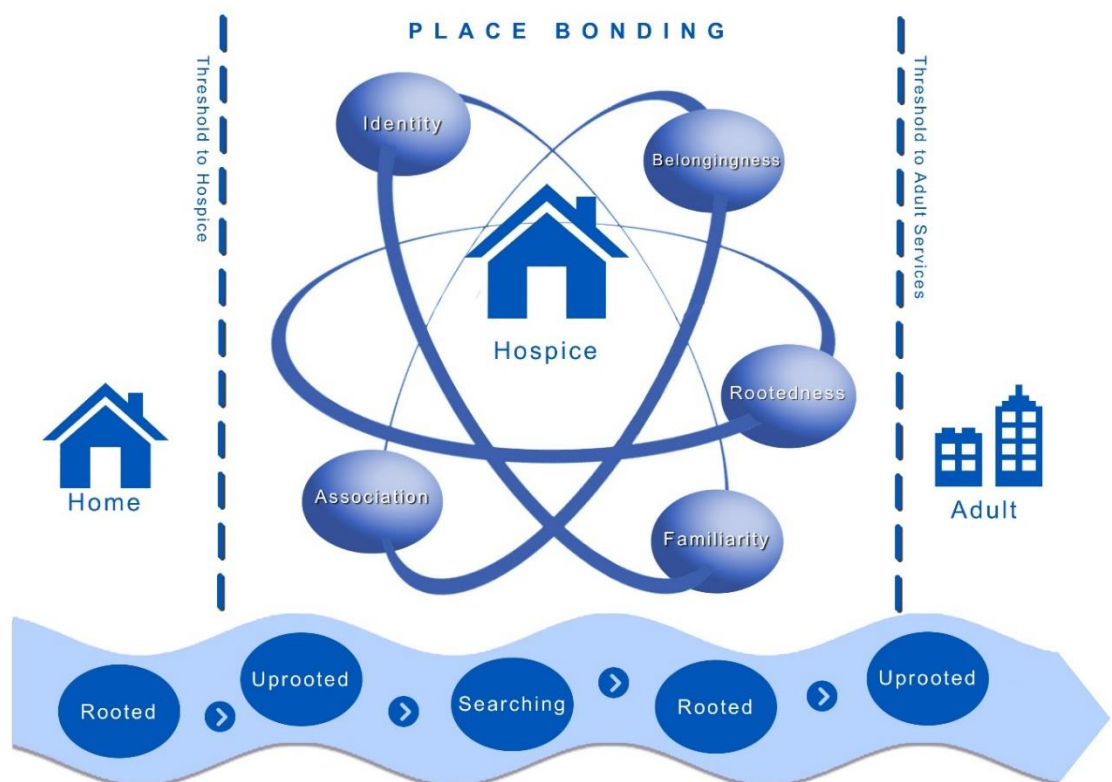


Figure 7.1 Illustration of the grounded theory developed, 'Place Bonding: Parents' journey towards a sense of rootedness in children's hospice care

The discussion that follows is a critical consideration of the five elements of place bonding: place familiarity, place identity, place belongingness, place association and place rootedness, and their application to the journey towards the hospice for parents of children with life-limiting conditions.

7.3 Uprooted – Crossing the Threshold from Home to Hospice

The parents were living in a world attempting to cope with the many physical and emotional demands that caring for a child with a life-limiting condition presented, as seen in other published literature (Whiting, 2014a, b; Steele and Davis, 2006; Eaton 2008; Kirk and Glendinning, 2004; Wray and Wray, 2004). The sense was that 'home' was the place where they felt secure, comfortable, where they experienced joy and belonging, it was a place of safety and security to take shelter, a place to be left and a place to return (Tuan, 1980; Moore 2000; Manzo 2003; Gustafson, 2001; Cristoforetti et al. 2011). However, over time some parents realised they needed help, a break from caring and some time for themselves. Ultimately this meant they needed to leave the familiarity of their home and search for another safe place that would offer the same sense of security and belonging that they experienced at home. Whilst many parents recognised that searching for a place of respite was something of a forced choice, ultimately the diagnosis which their child presented meant they would eventually need some form of help. It seemed that the search for help became a necessity to help parents survive. It was also evident that crisis situations at home or a deterioration in their child's condition forced some parents to accept their need for help.

Despite the many challenges that parents face the evidence suggests that it is difficult for parents to accept their need for respite care (Eaton, 2008; MacDonald and Callery, 2008). Whilst some parents continue to feel that getting help was a sign of not coping, the reverse has been shown to be true, and actually if parents had a break from caring they were able to cope much better with the demands of caring for a child with a life-limiting condition (Eaton, 2008). Despite the reported benefits of respite care that include improved sleep, freedom from constant caring, time to get other jobs done, benefits for siblings (Champagne and Mongeau, 2012; Welsh et al., 2014; Davis et al., 2004), it is parents' perceptions of respite care and how this is viewed by others which plays a critical part in

determining whether they will make use of services available (Macdonald and Callery, 2004).

It was apparent that parents were in a state of flux between deciding to continue caring totally on their own or stepping out and seeking help. This notion of being temporarily displaced reflects the temporal component and dynamic nature of individuals' relationships with place (Seamon, 1979; Gustafson, 2001). The state of being 'in between' is also reflected in the concept of liminality, used by Van Gennep (1960) which described a series of stages that people transitioned through when they changed social status for example. In healthcare the notion of liminality has been used to describe the disruption that illness poses on life (Frankenberg, 1986), in another example patients at risk of cancer have been described in the state of being in between two worlds, that of possible illness or health (Scott et al., 2005).

Whilst others have agreed with the notion that illness particularly at diagnosis forces a state of uncertainty and loss of control, they argued that in people with life-threatening conditions the notion of liminality is not necessarily a neatly defined staged process and may be more ongoing in nature (Little et al., 1998). Those parents who were not ready to accept the need for hospice services could be described as 'threshold people', in a transient state waiting to assume the role of hospice user or not (Turner, 1969). For those parents the idea of familiarity, identity, belongingness, association and rootedness could only be perceived as existing at home and not possibly available in any other place.

The irony was however, that for some of the parents, having finally made the decision to accept respite help and to seek an alternative place of belongingness (Baumeister and Leary 1995) actually finding a place to meet their needs proved difficult. Places where they could develop a sense of place bonding (Hammitt et al., 2004; 2006) were not available because there was limitation in choices available to parents. The lack of choice and availability of respite services is reflected in the literature as one of the largest unmet needs in children with complex and palliative care needs (Ventura, 2014; Whiting 2014b; Hunt et al., 2013). However, for some of the parents searching for a service led them to the hospice, a place whose identity presented them with more place related challenges they needed to overcome.

7.3.1 Gateway to the hospice - place familiarity

In order to come to terms with their need for help some parents in the study had to overcome emotional barriers, these included the idea of letting go of the control of their child, the guilt associated with what they saw as not fulfilling their parental responsibility and then eventual separation from their child by leaving them at the hospice and allowing someone else to care for them. This sense of feeling uncertain and out of control is akin to the experience of adults entering a hospice day care unit, who were described as drifting (Moore et al., 2013).

Parents came to realise that they could no longer provide for their child all of the time within their home. Acknowledging that they needed help and support also meant that they had to look for a place where this respite could be provided. Amongst limited options, this place was the hospice and the decisions to use it/or consider using it took different times to come to fruition. For some this was accompanied by uncertainty and for some the decision was made quickly if their child became very ill. For other parents, despite having a child with a life-limiting condition, they continued to battle with the decision to either accept help or continue to try to cope on their own.

The sense of uneasiness that parents felt at this time is similar to the notion of involuntary displacement described by Million (1994). Describing the forced relocation of five families from a dam flood area in Canada, Million (1994) explained how individuals first became uneasy, struggled to stay and then finally had to accept the need to move. This is also similar to a model of transition described by Tierney et al.'s (2013) study of the transition of young people with cystic fibrosis from children's to adult services. The first stage of the process was described as fracturing to reflect the need to break ties with staff in children services; the second stage, acclimatising allowed the young people to become more familiar with the adult unit and finally, integrating and being part of the adult unit. This notion of 'fracturing' can be seen in this study as parents grappled with the decision and heightened awareness that they had to consider care for their child outside of the home environment and potentially outside of their control. The sense of responsibility that they had as a parent was being broken. For some parents as they became more familiar with their place of respite in the hospice they started to 'acclimatise' to the idea of using the hospice.

Place familiarity is the process by which people develop their cognitive knowledge of a place (Hammitt et al., 2006). For parents place familiarity occurred in the context of acknowledging that their child would be looked after in the hospice by staff who knew and understood the needs of their child was vital. Respite was not considered a break if it did not adhere to the routines of the child; if parents had to spend time re-settling their child following a respite break then their perception was that the break was pointless. In some cases this also meant that the mind-set of the parents changed. The decision to accept their need for the hospice, balanced with their reluctance to acknowledge that there was nothing else, meant they had no choice but to accept the place they were in. The more familiar an individual becomes with a place, the stronger the sense of attachment and the stronger the bonds developed (Relph, 1976). Referred to as 'insideness' and 'outsideness', the strongest sense of 'insideness' was achieved where parents felt secure and ultimately safe in their location. Those parents who chose not to come to the hospice they remained in a state of outsideness, with no appreciation of what it had to offer. They continued to remain safe in their own home. The choices they made or did not make were perhaps confounded by the identity of the hospice, an identity which represented much of what they feared including their fear that their child would most likely die prematurely.

In most cases the decision by parents to take their child to the hospice was a deliberate one, often influenced by the desire to spend some quality time with other family members, to have some 'me' time and some needed rest. Fatigue has been shown to have a major impact physically and mentally for parents caring for children with life-limiting conditions (Steele and Davis, 2006). Parents recognised and acknowledged the benefits of intermittent rest and refreshment through their child's stay in the hospice. However, this had to be balanced against the anxiety they experienced in being separated from their child and their perceived sense of guilt regarding their parental responsibilities. This weighing up by carers of the benefits and costs of accepting help has been demonstrated in a systematic review of the literature related to adult and respite care (Ingleton et al., 2003).

In this study it was apparent that in order for parents to feel reassured about leaving their child they had to believe their child would be cared for in the same manner they were cared for at home. Therefore becoming familiar with the hospice was an essential

element of the bonding process. However, there was also a temporal element to this and for some parents whilst they liked the idea of help in caring for their child, making the decision to access the hospice took longer for some parents than others. For some parents leaving home created a sense of loss, a loss of control of parenting and a fear that their child would not be cared for as they would want them to. It also meant leaving what was safe, secure and familiar and stepping into the unknown.

In addition to crossing the threshold and leaving home, parents then had to physically cross the threshold and enter through the doors of the hospice. Hammitt et al. (2004) argued that it is possible with place familiarity to change an individual's perception of a place. The thresholds' concept was developed primarily to discuss student learning and curriculum design (Land et al., 2006). The threshold, described as a 'portal' is the opening up of a new perspective, a way of conceptually transforming and viewing in a different way what was previously hidden (Land et al., 2006). Once parents entered the hospice they very quickly began to realise that it was a safe place and they soon began to experience many of the characteristics which helped them to become more familiar with the setting. However, for some parents, 'troublesome knowledge' (Meyer and Land, 2003) demonstrated by their previous experience with a relative in an adult hospice settings, meant that letting go of existing negative thoughts regarding the identity of the hospice and crossing the threshold to enter was more challenging.

However, with time the perception and the image they had of the hospice changed and parents became integrated into the hospice and all that it had to offer and the third stage of the transition process was complete (Tierney et al., 2013). The process of place familiarity encouraged parents to visit the hospice more often and become more bonded by capturing a sense of its true identity.

7.4 Searching for a Place – Place Identity

For the parents in this study their identity as mother and father was subsumed in multiple roles aimed at caring and meeting the needs of their child with a life-limiting condition. The result was that for many of the parents their home became a place of caring, a more clinical environment where parents were focused on providing continuous care to their child with a life-limiting condition. The parents became the clinical experts for their child.

The issue of identity in relation to the physical environment was described first as place identity by Proshansky (1978) and is concerned with the way in which place influences self-identity. Place identity is described as a process whereby ideas, feelings, attitudes, memories, values and behaviours are formed regarding specific physical settings (Proshansky et al., 1983; Manzo, 2005).

The hospice offered parents the time and place to be themselves and, in doing so, enabled them to step sideways from some of their caring responsibilities to re-capture their identity. By leaving their child at the hospice or by having staff manage and provide their child's care, mothers described being able to be 'mum' to their other children rather than being their sick child's carer. For others it meant there was time to focus on being a couple. For the majority in this context the hospice redefined their parental role and allowed them 'to be'. In facilitating this move to being a 'normal' parent the hospice was like a bridge to the life they had anticipated (Manzo, 2005), a positive reminder about what life used to be like or what parents imagined life would have been like without a child with a life-limiting condition. This sense of enabling parents in their caring role to move for a short time from the front line to a standby position (Wray and Wray, 2003:204) is depicted in the personal story presented by David Wray and his wife of caring for their son with a life-limiting condition. As parents they defined their identities akin to living in two worlds, one world in which they were the parent and the other world where they were carer. Whilst they described their experiences of caring, problem solving and being an advocate they also referred to the consequences of caring: depersonalisation, lack of sleep, loss of privacy and personal space, loss of freedom and choice, social isolation and living in a house overtaken by resources aimed at meeting the needs of their son (Wray and Wray, 2003). This article demonstrates the importance of place identity and enabling parents to view respite not as a total detachment from their child but a chance for them to step aside for a short time from caring and allow their identities as mother and father to take precedent over their caring roles.

In order to encourage parents to take some time out from caring the parents in this study needed assurance that the staff who would be caring for their child would have good knowledge, skills and expertise. There was a strong sense that if parents felt staff were competent they were more likely to be able to 'place bond' and leave their child in a place offering respite. This has some resonance with further work on place bonding by Oh et al.

(2012) who noted that as their participants (anglers) become more skilled and knowledgeable they developed a history with a specific site, which in turn led to greater identity with the site and the likelihood of the development of strong bonds. In this study parents developed place identity through development of their knowledge of the hospice, that is place familiarity, and reassurance of the skills and knowledge of staff.

Relationships to places has been described as a way of determining self-identity in the world, markers in life's journey. Some parents in this study demonstrated what have been described elsewhere as 'milestone moments' (Manzo, 2005:76). Having taken the step to enter the hospice, a parent's experience was so significant that it resulted in a moment of realization of their need for help and support. Subsequently this experience mapped a point in time when parents recognised the hospice was in their life. It then became a place associated with the potential to satisfy the needs of parents and child and could be compared in some ways to their own home.

7.4.1 Thresholds of hope and masters of disguise

Whilst parents recognised the benefits of the hospice in caring for their child and offering parents some respite the reality was that entry to the hospice was by invitation prompted by the diagnosis of their child. Consequently the label of the hospice could be perceived as an indelible stamp, a reminder of the life-limiting diagnosis of their child. The idea that there are both positive and negative cognitions associated with place identity is discussed in the literature (Proshansky et al., 1983) however, the negative aspects of the phenomenon have been less explored (Manzo, 2003). The hospice is perhaps viewed as somewhat ambiguous as a place, set apart from the normal world because of the nature of the terminology used to describe it and the services it provides. For people who are not familiar with a children's hospice it exists as a place associated with illness, death and dying and as a result contributes to the negative connotations associated with the terms hospice and palliative care (Morstad-Boldt et al, 2006). In the same way the image created by the word 'hospice' influenced how parents interpreted the meaning of the place, ultimately influencing the affective bonds established with the hospice and their personal attachment to it. It was evident that there was something about the hospice, a drawing in affect, which facilitated parents staying. Creating an environment within the hospice that felt like home rather than a clinical institution can clearly be seen to be drawing on concepts of place familiarity. Consequently this manipulation of space meant

that parents perceived the hospice as a less threatening environment and more of a place of shelter (Vanclay, 2008). Alternatively it may be that because parents were so desperate when they got to the hospice, the sense of relief was overwhelming, they were able to sleep and so the meaning of the hospice as a place became fundamental to survival. For others the sense was that there was nowhere else, no other choice of service available. The result of the unexpectedness experienced was that parents stayed despite the realisation of the label.

Relph's (1976) theory of insideness-outsideness provides some rationale for the fact that many parents admitted not acknowledging the name of the hospice in the conversations they had at home or with friends. Entering the hospice symbolised separation for the parents; leaving a world where they were safe at home and entering another world which was confusing and strange (Manzo, 2003), one where initially they experienced a sense of 'existential outsideness', strangeness (Relph, 1976). Having a child with a life-limiting condition has been described for parents as akin to living a double life, one where they hope and long for normalcy in their daily life but also acutely aware of time and their child's illness (Sourkes et al., 2005). In order to cope with the uncertainty in their lives parents could be seen to consciously decide not to focus on the inevitability of their child's diagnosis (Sourkes et al, 2005, Benzein and Berg, 2005). Instead they concentrated on taking opportunities presented by respite to live as 'normal' families. Mothers found their role as 'mum' again, brothers and sisters had time with parents, and families experienced some rest and rejuvenation. Furthermore, in order to cope with the negative feelings associated with the word hospice there was a sense that parents masked the true identity of the hospice and the real reason as to why they qualified for entry.

When referring to the hospice, particularly in discussions about end of life, many of the parents described the hospice as having two faces, a dual role. Others described a closed door within the hospice, clearly a door that would not open unless they needed to, the door which took them to the other side of the hospice, the side for end of life care, the side where they would inevitably have to admit their child was likely to die early. Whilst it could be considered that parents were hiding from the truth, rather the sense was that choosing to see the hospice only in terms of respite was a coping mechanism for parents who were at the point of time in their journey with their child's illness trajectory that meant they did not need end of life care. Thus not all places within the hospice

encouraged a sense of bonding. In order to protect themselves from the notion of death parents entered the safest part of the hospice first, aware that there was another threshold they might have to cross. Even within the familiar place of the hospice, despite their efforts to hide from the truth, the parents were aware of another threshold that they might have to cross and knew it would create its own sense of displacement, disruption and uprootedness (Figure 7.2).

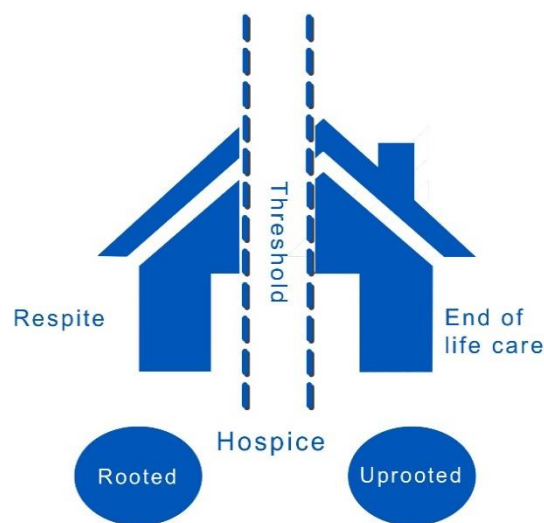


Figure 7.2 The two sides of the hospice

It was hard to know whether the hospice was good at hiding what it did or whether the parents hid from the truth as part of their coping strategy. Either way, both the hospice and parents became 'masters of disguises' and the feelings, memories and ideas which could have influenced place identity and subsequent bonding with the hospice were changed. For parents, whilst the disguise was a way of self-preservation, the reality was that for some of the parents one day the 'hidden door' 'in the hospice would open. When this happened, the parents and child would cross the threshold to the side of the hospice that they feared most and that they tried to avoid; the 'other side' would become a reality as their child approached end of life. For other parents as their children were living longer rather than cross the threshold within the hospice their future would involve being

uprooted from the hospice and transitioning to adult services to begin the process of bonding again.

7.5 Finding the Right Place - Place Belonging

In this study there were several characteristics which parents highlighted as desirable to enable them to feel a sense of belonging with any respite situation. The first characteristic identified by the parents was safety and security. Whilst many of the parents did not acknowledge the words palliative care they did recognise that the hospice was a secure and safe place to be, and, they appreciated it offered them a safety net, knowing that if their child did deteriorate a team was there within the hospice who would support the family through any difficult times ahead. A feeling of security is identified in the literature as an important part of the concept of relationship to places (Manzo, 2005). Feelings of safety and security are subsequently reflected in feelings of acceptance and being free to be oneself (Seamon, 1979; Manzo, 2005).

The concept of security and safety is highlighted in the literature more often in terms of one's own dwelling place. Chawla (1992) found that the most common form of attachment which emerged from childhood was the feeling associated with security and family love found in the home. Feelings of comfort derived from characteristics such as familiarity, rituals and routines were also found to be the most important aspect of home in a study of older women (Shenk et al., 2004). The notion of sheltering has been used as a term to depict the idea that within the hospice individuals could feel safe and secure (Moore et al., 2013). In this study parents began to develop roots within the hospice when they felt the staff caring for them were familiar with and knew their child. In this way establishing relationships and trust between parents and staff was vital. Furthermore the intrinsic desire to form healthy interpersonal relationships is fundamental to the idea of place belongingness (Hammett et al, 2006). However, these relationships must be longstanding, positive, stable and significant if belongingness is to be fully recognised (Baumeister and Leary, 1995).

There were several examples given in the study where parents expressed how at the hospice they had found somewhere where they belonged, how they were in the 'same boat' as others, how their child was with other children with life-limiting conditions and

how they as parents therefore had an affiliation with other parents. This sense of being part of somewhere where parents felt both they and their child were valued and accepted despite their life-limiting diagnosis created in parents a sense of place belongingness (Hagerty et al., 1992). The paradox was that a place the parents initially feared and did not want to enter and where their child's life-limiting diagnosis enabled entry, became a place of belonging, where parents viewed themselves as being part of the 'hospice family' and therefore gave them membership with the hospice environment (Hammitt et al., 2009). As parents experienced and interacted with the hospice again and again it became a more normal part of their world, one which they missed when they were not there. In this way repetitive experiences were seen to create a stronger sense of belonging to which an individual desired to identify more with (Kaplan and Kaplan, 1989) as also seen in Hammitt's work where a sense of return to the Chattooga River was evident amongst the anglers. Hammitt et al. described one group of participants as veteran anglers who had on average twenty five years' experience fishing on the Chattooga making an average of fifteen trips per year.

However, whilst safety and security, familiarity and knowing, continuity of care, trust and relationships were important characteristics which created a sense of belonging for parents and made the hospice a more acceptable place, the reality was that the experience was short-lived. Because of the nature of respite as a short break, parents were offered sixteen nights a year at the hospice. Many of them took these in short breaks of one or two nights, occasionally some parents booking their children in for one week at a time so that they could have a family holiday with their other children. Whilst all of the parents who used the hospice expressed a desire for more respite allocation there the reality was that their stay at the hospice regardless of length of duration was only a temporary situation. Despite this being a temporary situation, parents returned home knowing that there was an alternative place of bonding and a place where they had some association and were prepared to revisit.

7.6 A Quality Experience – Place Association

Place association, 'experience-in-place', is concerned with both the physical location and the nature of the experience (Manzo, 2005:74). In terms of physical location the environment in which a child is cared for has a strong impact on the child and can affect

the ability of the child's family to cope with their child's illness (Downing et al., 2014). Within the hospice the physical environment will either be perceived positively as attractive and non-threatening or the reverse (Downing et al., 2014). The external view of a building should offer visual reassurance there is nothing to fear. Ultimately first impressions count, and it is likely that parents will quickly decide whether the hospice could be an environment that will offer a sense of security and safety for their child. In this study whilst acknowledging the 'homely' feel to the hospice several parents expressed that the hospice looked like an office building. In previous published literature (Worpole, 2009) good design has been shown to help orchestrate emotions. In response to early findings Woodlands has reviewed their reception area and plans have been drawn up to create a larger, more welcoming space for children and their families. Creating a sense of connectedness in a building also facilitates the notions of place belonging and place association (Downing et al., 2014).

The positive association with place is also demonstrated in the relationship between health and disease described in the notion of therapeutic landscapes (Gesler, 1992, 2005). Gesler (1992) proposed that healing and place are inseparable and that certain places potentially can have a positive effect on an individual's health and well-being. Implicit in the idea of therapeutic is the notion of a positive experience, the argument being that in order to create a therapeutic environment the physical, psychosocial and spiritual aspects of patients, families and staff should be satisfied (Smith and Watkins, 2010). In the hospice the bedrooms were designed to reflect an environment like that of a child's bedroom at home. Bright art work, child friendly décor, communal dining areas and a friendly relaxed atmosphere were physical characteristics of the environment that parents identified with and which influenced their sense of place association and identity (Giuliani, 2003).

The second way that bonding is achieved through place association is in the nature of the experience. In the study there were a few parents who had experienced a hospice with an older relative. The view held that an adult hospice was a place of calm, of dying, of remembering and of making every moment count was a barrier and a 'bridge to the past' (Manzo, 2005) that parents did not want for their child when they were simply seeking respite. Individuals will consciously choose which places they use, influenced by their view on how the particular setting provides an environment appropriate to its use and

how it will satisfy their needs and goals (Raymond et al. 2010). Consequently individuals make an assessment of the quality of the place (Stokols and Shumaker, 1981; Manzo, 2003); how much they talk about that place and its qualities is a measurement of an individual's attachment to a place (Vanclay, 2008). Memories from previous experiences will also drive how individuals perceive a place in the future (Inalhan and Finch, 2004).

As previously discussed there was a sense that within the hospice there was a masking of the real reason for the place and that against their expectations many parents perceived the hospice environment as a nice place to be. Furthermore the environment that parents experienced created in them a sense that the hospice was all about living and not dying, a contrast to their perception of adult hospice facilities. Associating the hospice with a sense of living meant that parents perceived their experience at the hospice as positive, and in this way they recaptured a little of the quality of life that some of them perceived they had lost for themselves and their child. Despite not using the terminology 'palliative' parents recognised that life for their child was limited and whilst they did not want to associate the hospice with dying they did recognise that it was a safe place to be in case their child deteriorated and became ill. Having a sense of place familiarity and place belonging meant they had security in knowing that there were professionals they trusted to care for their child during difficult times such as their child's deterioration. Consequently as also seen in Downing et al.'s (2014) work it appeared that the hospice was a successful building serving the purpose of its users and the organisation it houses. The glimpse of 'normal' life that the hospice gave parents was also fundamental in achieving a sense of place association.

7.6.1 Encountering a sense of normality

Most parents in the study described their life with a child with a life-limiting condition as not normal. In the context of their expectations of being a parent they perceived their world as different, a world set apart from those of other parents around them without children with an illness. Whilst the intricacies of what constitutes 'normal' is debateable the sense in this study was that many parents felt 'robbed' and as a consequence they held onto the illusion of what they believed was normal. Maybe it was the before and after effect of what their life was like before their child with a life-limiting condition or the recognition of what life was like now and the dread of what was to come which affected their perception of normal. Either way for the parents in this study their focus was on

maintaining a sense of normality in their lives. This desire to achieve some normality is also highlighted in the literature as a vital component of coping, a process of bracketing out the impact of the illness (Price et al., 2011; Wood et al., 2010; Steele, 2000; MacDonald and Callery, 2004). Consequently any place that parents would bond with needed to have the potential to satisfy this desire for normality.

Evidence suggests that there are many things which differentiate the world of a parent with a child with a life-limiting condition from the 'real' world. The inherent battle and fight to access help and resources, adherence to schedules, uncertain futures, loss of potential for their child and the fact that their time was never their own were demonstrated both in this study and other literature (Whiting, 2014a; Bray et al., 2014; Steele and Davis, 2006). As a result of these many challenges parents perceived that they were left behind as life moved on for everyone else around them. The inference was that time or the pace of life was somehow perceived differently for these families. Arguably the restrictions parents faced by having a child with a life-limiting condition may have made them feel as if they were losing out and therefore being left behind. However, on the contrary the intensity of caring could mean that time passed much more quickly for parents, albeit this was not something parents' perceived.

Nonetheless, for a short time whilst at the hospice parents experienced the potential of the hospice to satisfy their needs in terms of achieving normality in their family life. Concurrent with other studies (MacDonald and Callery, 2004; Welsh et al., 2014) the hospice gave parents the freedom to engage in normal family activities without tedious planning and to experience a sense of spontaneity in their lives. This association with normality at the hospice had a powerful therapeutic effect on parents enabling them to experience rest and restoration. Moreover the hospice became a lifeline for many parents (Eaton, 2008). The hospice also became a place associated with giving parents some control in their lives.

However, there was one group of parents whose view was that the hospice was not fully meeting the needs of their children and for this reason the positive strength of place association with the hospice was reduced.

7.6.2 The piece of the jigsaw that did not fit – place association for young men with DMD

The perception of the parents of the young men with Duchenne muscular dystrophy (DMD) was that because the needs of these young men was different from other children at the hospice, therefore in terms of place association the hospice was not a place that would help them meet their everyday goals. Parents believed that the intellectual abilities of the boys meant that their goals were different from those of other children at the hospice who did not have the same level of mental capacity. This affected their idea of place association and they became the part of the jigsaw that did not seem to quite fit at the hospice. As reflected in other work it was apparent that within the hospice parents agreed that adolescents needed their own space, away from adults, to be able to listen to music and watch television, to make their own decisions and have time for socialisation (Downing et al., 2014). Whilst the parents of the group of young men with DMD acknowledged the benefits of the hospice for children with complex needs their view was that despite being physically challenged their sons were mentally able and therefore they needed a place of respite which offered more than the hospice did in encouraging independence and responsibility.

Arguably within a respite environment the idea that 'one size fits all' is not appropriate (Welsh et al, 2014:105), the evidence with children with complex needs has shown that the need for respite changes over time as children develop and grow (MacDonald and Callery, 2008). In terms of architectural space, age is directly related to space requirements and adolescents and young adults need different spaces. It is a natural instinct for adolescents to want to increase their independence and control over their own care. The conflict for young men with DMD is that this often comes at a time when their condition means that they are physically more dependent on others (Maunder, 2004:594). When most people of their age are deciding on their personal goals and looking towards the future, the choices for young men with DMD become fewer. In this study despite parents' expressing there were no alternatives for respite care, the association was that this did not mean that the hospice was necessarily the right choice for their sons.

Parents believed their sons wanted to use the hospice as a social hub, somewhere they could come to meet with other boys with DMD, hang out together and enjoy living life

rather than winding down. In this sense the idea of place belonging was perceived as important. However, the reality was that for the majority of them when they came to the hospice they were often the only person with DMD there. Additionally, because of the nature of a children's establishment there were many restrictive covenants, for example certificates of movies placed on them that meant they could not do the things they wanted to do or were normal for them to do at home. In this way their sense of place belonging was threatened. Whilst place association at the hospice was perceived as positive by the parents of other children with life-limiting conditions the idea of place association for boys with DMD was more of a neutral concept. Parents appeared to have a heightened awareness of the skills and competencies required to care for their sons.

In a recent study (Kirk and Fraser, 2014) the differences required for place association amongst parents with children with life-limiting conditions and who are cognitively challenged as opposed to those parents with young people who despite physical disabilities are more cognitively able were evident. Kirk and Fraser (2014) suggested that the best way for children's hospices to support the ageing generation of young people with life-limiting conditions was by adopting an advocacy role and encouraging empowerment and independence amongst this group. In addition they also suggested that the priority for staff for this group of parents and young people was offering more emotional and psychological support to parents and young people as opposed to physical care. Despite having a separate young person's unit attached to the hospice the findings from Kirk and Fraser's (2014) work identified that providing an appropriate building was only one aspect of support required for this group of young people. Similar to the idea of place association in this study Kirk and Fraser (2014) showed that it was the functionality of the hospice in meeting the differing needs of this group of young people that was important. Whilst there is evidence to suggest that children's hospices are now supporting more young people over the age of 16 years (Devanney and Bradley, 2012) it may well be that the dimension of place association is dependent on age and diagnosis, therefore services will need to adapt to meet the changing needs of an ageing population of children (MacDonald and Callery, 2008).

7.7 Rootedness – Coming ‘home’

The parents in this study were experienced in using the hospice; the average length of time using the hospice was eight years but there were some parents who could be described as ‘veteran’ users (Hammit et al, 2004) and had been using the services at the hospice for nearly twenty years. Repeated use and positive experiences led to a sense of place rootedness for the parents defined by feelings of safety, being known at the hospice, parents feeling secure and comfortable and therefore at home within the hospice. This correlation between time spent in the hospice and attachment also meant that the parents in this study were less willing to leave the hospice again. The sense of bonding experienced meant for some of them there was a sense of disappointment when their respite break was over.

Despite the fact that the findings of this study demonstrated parents’ desire for place association and rootedness at the hospice and place bonding took place there was something of a sense of it not being perfect. Not everything about the hospice was pleasing and not everyone was pleased. Whilst Hammit’s (2004, 2006) work demonstrated that anglers were familiar with, belonged to and identified with the Chattooga they were not necessarily dependent on it or felt rooted in it. Recreation places are places that individuals visit to undertake an activity. In Hammit’s work there were many alternative river places for the anglers to fish which meant that strong dependence and rooting bonds were not often apparent. Limited choice and lack of provision of places for respite for children with life-limiting conditions no doubt influenced the fact that parents kept returning to the hospice. Whilst place of ‘home’ is not always perfect for everyone the emotional implications of feeling at home in a place contributed to the sense of rootedness parents experienced (Antoinch, 2010). This feeling of rootedness is one of the pre-requisites of the experiences eluded to by Seamon’s (1979) ‘at-homeness’ and intrinsic in the notion of insideness and outsideness described by Relph (1976).

However, for many parents at the hospice there was an acute awareness that their child was getting older which meant that they could not stay at the hospice forever. The anxieties of parents in this study regarding transition to adult services were evident. As parents experienced the elements of place familiarity, identity, belongingness and association with the hospice a stronger sense of insideness was experienced. This deep

sense of rootedness is why the idea of transition into adult services, being uprooted again and being forced to relocate was so detrimental to the parents in the study. The idea of having to establish new routines, get to know new people and services, meant that the idea of transition would be a time when parents would expect to feel alienated and alone, and once again experience a sense of 'outsideness' (Relph, 1976).

7.7.1 Thresholds and new horizons – transition to adult services

Even from a very early age parents were worrying about the future for their children. For some parents because of the developmental delay their child experienced the perception was that their child would always be a child. Services dictated that over the age of eighteen their children were adults and as such needed to transition to adult services, however, the common view amongst parents was cognitively their children would never be adults. With many children surviving longer (Fraser et al, 2011b, 2013) children who have survived into adulthood but would never cognitively be an adult, created a huge tension for parents. From feeling safe and secure in the hospice, parents were faced yet again with the prospect of uprootedness, another looming threshold to adult services and moving from a place they had bonded with to another unknown setting.

All life is episodic and transition is a normal phenomenon such as when a 'normal' child moves from primary to secondary school. Whilst there are still expected phases and milestone events for children with life-limiting conditions these appeared more intense and heightened due to time. Despite the strong sense of direction of travel towards a time when their child would need end of life care, there was no way of knowing when that time would come. Instead many parents were experiencing a much longer journey than they had expected or had been told at diagnosis. In addition to the uncertainty of their trajectory of their illness, parents were anxious that as they moved forward towards transition to adult care the many services they had fought so hard to get would be lost, some believing that in terms of respite they would be left with nothing in terms of respite.

As children with life-limiting conditions are surviving into adulthood (Fraser, 2013) a whole new generation of young people is being created that adult services and adult professionals have little experience in dealing with (Doug et al, 2010). Traditionally transition and ultimately the provision of palliative care for adults has veered towards adults with advanced progressive illness and malignancies (Doug et al, 2010).

Consequently managing the demands of young adults with a plethora of complex conditions, symptoms and multiple co-morbidities may be potentially challenging. (Kirk and Fraser, 2014) Providing respite services in adult settings where parents of young adults with life-limiting conditions experience the dimensions of place bonding identified in this study may pose a challenge for the future, particularly when relatively small numbers are dispersed across many adult services. In addition as demonstrated in this study there are different needs between young adults with life-limiting conditions who are cognitively able as opposed to those who are cognitively challenged. This has a bearing on place association and ultimately place rootedness. Nonetheless the idea of finding a place and providing places that can offer the same sense of place bonding as the children's hospice may prove difficult.

7.8 Conclusion

The findings of this study demonstrate that over time affective bonds develop between parents of children with life-limiting conditions and the hospice. When present, place familiarity, place identity, place belongingness and place association led to a deeper sense of place rootedness and established bonds with the hospice.

In place familiarity parents found somewhere where they experienced the same sense of safety and security that they experienced at home. Parents formed relationships with staff who knew their child, were familiar with their routines and competent in caring for their child. This in turn led to a stronger sense of belongingness and a feeling that as parents they were not on their own, there were other parents with whom they could share similar experiences. With place identity the hospice offered parents time to be themselves, to grab a glimpse of what they perceived as 'normal' family life, to take a step sideways from some of their caring responsibilities in an environment associated with meeting the needs of their child with the life-limiting condition. Whilst there was ultimately a side of the hospice that parents feared most, a side where they would do their utmost to avoid, experiencing a sense of bonding offered some reassurances that when the time for end of life care with their child approached the same sense of bonding would help them through that difficult time. Finally the concept of rootedness portrayed the sense that parents in their search had finally found a place where they belonged and where they truly felt at 'home'. In this way finding a place where parents experienced a

sense of bonding potentially made the decision to accept help and support in caring for their child with a life-limiting condition more manageable. The hospice was more than just a location, it was more than just a respite service, the hospice possessed meaning, identity and was a place where parents could form attachments with.

Chapter 8 Conclusions and Recommendations

This final chapter will present the implications for clinical practice based on the key findings of this study. Following this recommendations for practice and policy in the region and beyond are offered. However, before doing so the challenges faced in ensuring trustworthiness of the data and the strategies in place to ensure that rigor was maintained during the research process are first explored. The limitations of the study are considered to allow genuine interpretation of the findings and judgement of the conclusions and recommendations. Finally, proposals for dissemination of the findings of the study together with areas for further investigation will be highlighted.

8.1 Evaluation of the Quality of this Study – Personal Reflections

Throughout the qualitative research literature various terms and techniques are used to describe criteria for evaluating the quality or ‘trustworthiness’ of the research process (Morse et al., 2002; Bryman 2012; Nolan et al. 2003; Guba and Lincoln, 1981; Lincoln and Guba, 1985). The most widely known are the four criteria described as: ‘credibility’, ‘transferability’, ‘dependability’ and ‘confirmability’ (Lincoln and Guba, 1985).

Research is deemed credible if the results are trusted and valued. This means that individual experiences are interpreted and described accurately (Guba & Lincoln, 1981; Sandelowski, 1986; Lincoln & Guba, 1985). In grounded theory **credibility** relates to the process whereby the categories developed come from the data, that is, they are discovered rather than preconceived. This means that the theory generated is accurate in terms of how well it describes the phenomenon being studied (Chiovitti and Piran (2003). **Transferability** or fittingness pertains to the notion that the findings have meanings and are applicable to others in similar situations (Guba and Lincoln, 1981). In constructivist grounded theory knowledge is transferred from one setting to another via a process of vicarious experience (Guba and Lincoln, 1994). Therefore sufficient detail must be provided so that another reader could follow a ‘decision trail’ of the theoretical, methodological and analytical choices made at each step in the research process and, subsequently produce similar conclusions. By doing so the **dependability**, that is, the consistency, repeatability and accuracy of the study is demonstrated. Finally

confirmability is about establishing auditability, applicability and truth value. In grounded theory this has been described as 'work' and 'relevance' (Glaser, 1978) and relates to the fact that transparent links are shown between the data and the interpretation of the data. As a result the developed theory should be able to explain what is happening in the area of investigation.

Whilst these criteria are useful to evaluating trustworthiness they do not in themselves ensure quality of a study. Drawing upon the work of Morse et al. (2002), Chiovitti and Piran (2003) and Charmaz (2014) the discussion that follows below will highlight the processes which were adopted in this study to enhance the trustworthiness of the grounded theory study.

8.1.1 Researcher responsiveness

Constructivist grounded theory acknowledges researcher involvement (Charmaz, 2014) and one way in which work may be evaluated is by the extent to which researchers record their involvement. Throughout this thesis an attitude of self-awareness and reflexivity was demonstrated and documented. The criteria built into my thinking were detailed in the exploration of the ontological and epistemological assumptions that both guided the choice of methodology and the approach to the analysis. As a strategy to enable reflexivity thoughts, feelings, decisions made, processes followed and problems encountered were recorded in a project journal. During the process of data analysis as nodes were developed in NVivo comprehensive descriptions highlighting the researcher's thoughts and the reasons for labelling the data in a certain way were made. Memos recorded decisions and intuitive thoughts about the data. Records of accounts of all supervision were also maintained. I endeavoured to stay open and flexible during the process of data collection and analysis (Charmaz, 2014), developed my theoretical sensitivity, whilst relinquishing any ideas that were not supported by the data (Morse et al, 2002).

8.1.2 Methodological coherence

Chapter 3 presents sufficient detail of the theoretical and methodological choices underpinning the study and the decisions made at every step of the process of data collection and data analysis to enable the reader to check the 'decision trail' of the study. A basic belief within constructivism (Charmaz, 2014) is that while all experiences are

unique, findings in one context can have some applicability in another. By presenting enough detail regarding the scope and context of this study and presenting details of the sample and setting, readers can see how the findings map to and align with their own practice, experience and settings. Although the demographic details of the parents and the children were presented this was not depicted in great detail. The level of detail chosen aimed to create a picture of the context from which the themes and theory were developed to enable readers to draw their own conclusions relating to the applicability to their particular setting without breaching the anonymity of the parents and their children. However, some useful nuances will not have been reported as a result of prioritising anonymity over depth of detail. Adhering to various processes (described below) for recruitment, data collection and analysis during the conduct of the study enhanced the credibility of the findings.

A process of purposeful sampling was adopted to ensure that participants selected would offer as much knowledge and experience and as many insights as possible to the study. In phase 1 attempts were made to include all potential participants by inviting all parents who used the hospice to participate in the study. In both phases parents were recruited using an opt-in strategy and I did not influence the selection procedure.

In keeping with interpretivist ontology and acknowledging that multiple realities exist both methods of data collection (focus groups and interviews) facilitated a process of self-reporting and interaction and allowed participants to tell their own stories in their own way. As such the information received was revealing in terms of what parents wanted to share. Whilst I used a topic guide in the focus groups and interviews to ensure that similar areas were covered there was also flexibility for individuals to freely express their experiences and bring their ideas into the study. Adopting the dialectic process of clarifying understanding and exploring alternative explanations was key within the constructivist approach of the study.

The process of memo writing was used to keep a record of my insights and analytical ideas during data collection and analysis and to make explicit the process of creating categories. Knowing that inaccuracies within the process of transcription of data can compromise the trustworthiness of the findings, each recorded interview was checked carefully against the transcript. In addition, a member of each focus group was randomly selected and given a

summary of the report of their focus group to ensure it represented the overall contributions accurately and fairly as suggested by Chiovitti and Piran (2003).

The systematic and transparent process adhered to during data analysis was described in detail to enable the reader to clearly identify and evaluate how the researcher interpreted the findings. As patterns emerged from the initial focus groups these were cross checked within later focus groups thus adding to the methodological coherence and credibility of the findings.

Although direct comparability is impossible, by accurately describing the context and the theoretical framework behind the methodology, other readers are invited to reach their own conclusions as to whether the work presented can be compared with another situation and their own experiences. During interviews in phase 2 there were four participants from the hospice aware group who were using neighbouring hospices outside of the region and who described similar feelings, perspectives and views as the participants in the hospice user group. This led me to believe that there would be an element of applicability for other children's hospices, but ultimately this will lie with the publications, presentations and other forms of dissemination that come from this study and how other hospice services and parents view the results.

8.1.3 Theory development

Koch (2006) suggests that a research study can be shown to be dependable when the "decision trail" can be followed by another investigator and the conclusions generated are similar or comparable. This was particularly important with the development of the grounded theory. In this study collecting and analysing data occurred concurrently. This meant that there was an iterative process of going back and forth between data collection and analysis and meant that interpretation was grounded in the data. The strategy of memoing and recording details in a project journal reflected the development of my abstract thinking. The original copy of each transcript was preserved and used to constantly compare data and emerging categories both with the steering group and my supervisors. The analytical reasoning process detailed in the data analysis section of the study offered insight into decisions made during interpretation and construction of ideas. The initial review of the literature was undertaken to provide a rationale for the study. A

subsequent review related to the theory was not conducted until after the theory was developed and therefore limited any bias.

Using the words of participants in labelling codes and investigating new areas that emerged during interviews, meant that participants guided the research process which in turn enhanced credibility (Chiovitti and Piran, 2003). A detailed description of the findings using participants' own words and excerpts from interview data is presented in chapters 4, 5 and 6 in a narrative description. Consequently data could be tracked to its source and the 'decision trail' of how interpretation and generation of themes emerged within the narrative was explicit. Careful consideration was also given to the process of 'member checking' as to whether transcripts should be returned to parents to enable them to review and clarify their contributions. However, the decision was made not to return them to parents for two key reasons, the first being methodological and the second one ethical. Based on the understanding within a constructivist approach that multiple realities exist and that the transcripts would represent a subjective and relativist account of the parents' experiences it was not felt necessary to return the transcripts, especially as there were no areas in the transcripts that prompted the need for clarification. However, in some sense there was a process of checking that arose as a natural part of the study. The data were analysed and collected concurrently, and emergent concepts and ideas were woven into subsequent interviews with parents. This provided opportunities for ensuring that emergent ideas resonated with the parents.

The second reason for not sending transcripts to participants for 'member checking' was ethical. 'Member checking' has been described in the literature as either a beneficial process or one which has the potential to cause upset (Birt et al., 2016; Carlson, 2010). Due to the sensitive nature of the study various processes were in place to support participants and ensure no harm was caused; it was felt that returning transcripts to parents could have resulted in an additional intrusion and could have been an insensitive approach to take (Birt et al., 2016). Using direct quotes in chapters 4, 5, and 6 brings the reader as close as possible to the experiences of participants, demonstrating the degree to which the analysis was grounded in the data.

Glaser (1992) warns against forcing data into preconceived data labels. Whilst it was important to ensure that categories created were the best possible fit for describing the

meaning of the data, chapter 3 clearly demonstrates the emergence of the themes. Frequent debriefing conversations occurred with both my supervisors and the steering group set up to scrutinise the conduct of the study enabling further evaluation of the study. These conversations offered a process of challenge and discussion to further add insight and development to the themes that were emerging and helped to ensure that the themes resonated with members of the steering group and supervisors. In chapter 7 the links between the data, analysis and arguments are clear and sufficient information has been presented to merit the theory developed. I believe that my grounded theory extends the idea of place bonding to the place of the hospice and will form the basis for further work in this field.

8.2 Acknowledging Strengths and Limitations of the Study – Personal Reflections

From a methodological perspective a strength of the study is that a constructivist grounded theory methodology fitted well with the research design, philosophy and question, and enabled an in-depth exploration of the perspectives and experiences of palliative and hospice care for parents with children with life-limiting and life-threatening conditions.

This study was based on the experiences of thirty eight parents of children with life-limiting and life-threatening conditions in one region in England. Despite considerable efforts to recruit parents, the response rate was lower than initially expected. The difficulties in recruiting participants within the field of children palliative care are well recognised in the literature, and there was no way of knowing if the information that staff within the participating centres gave to parents was consistent or accurate or delivered in a way that was committed or engaging. Similarly in phase 2 of the study the effort that was put into recruiting was solely dependent on the teams of community nurses. Differences across the seven teams suggest that there was an element of gatekeeping in place and/or some teams were more committed to approaching parents and asking them to consider participation. However, difficulties in recruiting did not distract from the richness of findings. In grounded theory participants are recruited until theoretical saturation is reached. Arguably whilst it is always possible to continue to explore ideas in greater depth, the analytical process of constantly comparing the data sufficiently

demonstrated that the same patterns and key themes were emerging consistently. The number of participants in the study who were not hospice users was small. Whilst appreciating their views may not represent the views of other parents who did not use the hospice the paucity of research in this area make the findings worth noting.

Whilst qualitative research does not seek to produce findings which can be generalised to a larger population I believe that the depth of the information provided significant insights into the area of hospice care and enabled a theory of bonding to the hospice to be developed. Consequently the findings of this study have the capacity to influence other parents, staff and managers at the hospice, and the seven community teams. Beyond this there is the potential to have wider influence and implications for children's hospices nationally and internationally.

Whilst it is important to understand the views of parents, one of the main limitations of this study is the absence of accounts from children and young people with life-limiting conditions and from their brothers and sisters. Obviously there are many children with life-limiting conditions who have poor verbal and other communication skills. However, as demonstrated in this study there is a generation of young people who use the hospice due to significant physical disabilities but who are cognitively able. Adding their voices would greatly enhance the findings of this study.

As a novice qualitative researcher I recognised the limitations of inexperience. Using focus groups and interviews as methods of data collection were revealing in terms of the richness of data collected. However, facilitation of the interviews was at times both challenging and frustrating. In the first focus group inexperience as a researcher meant that sometimes it was difficult to remain focused and not engage in conversation at the same time as not leading participants. There were a few occasions during individual interviews when it was noticeable that participants were guarded in their responses. However, as the study progressed my expertise developed and as I became more relaxed I found it easier to prompt and encourage exchange. There were also times during the transcription of data where I was aware that I had missed opportunities to explore questions further, however the data gathered was rich in content and sufficient to inform the study. During the process of analysis and interpretation of the data I was often consumed by doubts and anxieties about the theoretical approach adopted. Whilst there

is always the potential with qualitative data to develop and expand theoretical insights and make new connections I am confident that the theory developed in this study is grounded in the data and thus the perspectives and experiences of the parents.

Constructivist research should encourage action (Brown Wilson and Clissett, 2011). Therefore, it would be inappropriate to conclude this thesis without considering the implications for practice, education policy and research.

8.3 Key Findings and Implications for Clinical Practice and Education

Whilst many of the implications for clinical practice relate specifically to Woodlands it is anticipated that readers may feel that these resonate with other services that offer palliative care and respite to children with life-limiting and life-threatening conditions. The aim of this study was to explore how the needs, experiences, use and acceptability of children's hospice and palliative care services would inform new ways of delivering services for children with life-limiting conditions and their families within the region. Whilst this study has revealed that parents recognised their current and/or future need for help in caring for their child it also shows that accepting respite help was not an easy decision and it took time. Barriers in terms of lack of choice, their perception of the hospice, geographical distance, anxieties and guilt about being separated from their child, existed and discouraged parents from accessing help. In thinking about the choices and decisions they needed to make, their sense of rootedness at home was disrupted as they began to search for another place, the right place for their child to receive equal to the care they received at home. Whilst it was really difficult for parents to overcome the many challenges presented and accept the need for help, the hospice became a place to which parents formed an emotional attachment.

From the findings of the study a new framework has been proposed which illustrates the bonds which develop between parents of children with life-limiting conditions and the hospice. It is anticipated that this framework will offer insight for professionals and carers into the dimensions of place bonding: place familiarity, place identity, place belongingness, place association and place rootedness. When present these five dimensions foster a sense of belongingness and reassurance for parents that they made the right decision not only to seek respite help but also have made the right choice of respite. In order to experience a

sense of place familiarity and belongingness certain characteristics were desirable: a feeling that the hospice could keep their child safe and secure; their child was being cared for by staff who were competent and knowledgeable; staff were familiar with their child and understood their child's routines, paying attention to detail; and finally, staff took time to build trusting relationships with parents and children. When these characteristics were present the hospice became a place that engendered a sense of belongingness for parents and encouraged parents to access the hospice for respite again and again.

Additionally the study has illustrated the paradox that parents face as entry to the hospice, a place parents grew to feel they belonged, was because their child had a life-limiting condition. The positive and negative connotations associated with the identity of the hospice and the influence that this had on parent's self-identity affected the time it took for parents to bond with the hospice. Living with a child with a life-limiting condition meant that parents experienced many restrictions and loss in their lives. Compared to other parents around them, the parents in this study perceived their lives with a child with a life-limiting condition as different, not 'normal'. Because of this many of them yearned for normality and what they perceived parents with 'normal' children have. Respite services offered at the hospice offered parents' rest and relief from constant caring, time to do normal things for themselves as people, such as: sleep through the night, eat their dinner uninterrupted, and some time to do normal things as a family. However, the reality was that allocated time at the hospice was limited and parents wanted more.

The image associated by the word hospice influenced how parents interpreted the meaning of the place, ultimately influencing the affective bonds and their personal attachment to it. Parents perceived a hidden threshold within the hospice, separating the two sides of the hospice, the respite side and the end of life care side. Whilst there was an underlying sense that they knew the hospice was partly a place of dying, the disguise that existed meant the hospice was a place where parents found comfort, a place like home, a place where they did not have to think about the potential future and where they could concentrate on today and not tomorrow. Rather than reinforce negative preconceptions, staff are in a position to create an environment which helps parents experience a place which is different from what they had expected, and create a place like home. From conversations occurring during the course of this study there are plans to redesign the hospice entrance creating a sense of place association which is focused on welcome and

positive experiences, and most importantly an environment in which parents want to connect with and are prepared to venture further into.

Children with life-limiting and life-threatening conditions are surviving longer; consequently the 'journey' for parents was much longer than they ever anticipated. Whilst uncertainty existed in terms of the progression, path and timing of the end of the journey, transition into adult services was a very real possibility for some children and parents, and a time of further challenge. The concern was that the parents and child would be uprooted from their familiar place at the hospice and have to start the search to find another place to create roots within adult services. Parents would begin again the same sort of processes and decision making they underwent in coming to terms with Woodlands, albeit this time it would be different as they had some concept of the value of respite help. However, the challenges of crossing another threshold would be present as parents determined whether adult services would offer a place with which they could bond with. Ultimately parents and child were faced with saying goodbye to the services and carers with whom they were familiar and to whom they had established relationships and become attached to. It was also clear that some parents also perceived that their son or daughter would always developmentally remain a child. For this reason these parents believed that adult services would never be the right place in which their child should receive respite. However, children's hospices are potentially in an ideal position to support and encourage transition by giving parents information about adult services. By working collaboratively and in partnership with adult services, including adult hospices, options like joint visits could be facilitated. Key workers from adult services could be identified to gain the knowledge, skills and competencies required to care for young people transitioning but also reassure parents that many of the characteristics they identified in children's service are present in adult services.

There was a group of young people primarily with Duchenne muscular dystrophy accessing the hospice for respite services whose parents did not feel it was the right place for them to receive respite. Parents' views were that because of their sons' cognitive ability and mental capacity these young men had different needs from the children and young people at the hospice who were not as cognitively able; these needs were not being met by the model of care offered by the hospice. Encouraging advocacy, independence and teaching life skills in this group of young people could better prepare them for taking

their next step into adulthood and adult services. Scheduling respite visits to enable some of these young men to be at the hospice at the same time, to enjoy socialising together and facilitating peer support would be one way for the parents of this group to view the hospice as a more appropriate respite environment. Also the idea of having weekend 'respite camps' for this group of young people would potentially mean that the rules and restrictions parents perceived at the hospice could be more relaxed and their sons could experience respite as more of a holiday.

When elements of place familiarity, place identity, place belongingness, place association existed the idea of place rootedness in the hospice reflected the sense that parents had finally found a place where they belonged and where they felt at 'home'. For parents who had no experience of the hospice finding a place which met all the characteristics for belongingness was something they aspired to but had not yet found; these parents continued to stay in the safety of their own home, choosing not to venture across the hospice threshold.

As presented above there are a number of recommendations for clinical practice that have emerged from the findings of this study and they are presented below. In addition, as a result of the process of feeding back to the steering group and the Board of Trustees at the hospice it was possible following the completion of phase 1 to make some early recommendations to influence future service development at the hospice. In response to the notion that certain characteristics, if present, fostered a sense of place familiarity and belongingness for parents a project proposal - 'A Hospice without Walls' service - for increasing the outreach work of the hospice was developed. This service proposed a number of key initiatives to maximise the contact and impact with families throughout the region by extending support beyond the framework of the hospice building. A feasibility study to release care staff from the hospice to offer home care at end of life has been proposed. In addition a 'Family Support Plus' service will offer families whose child is entering the end of life phase half day visits of care to either enable the family to get a break or to join the family to enable them to do something that they would not feel comfortable to do alone for example, go for a walk. The aim being that place bonding achieved at the hospice will be replicated into the child's community.

8.4 Recommendations

Whilst the recommendations below are specific for Woodlands and the palliative care teams working within the region it is anticipated that they may resonate with other providers of palliative care services. Recommendations are also made for policy.

8.4.1 Recommendations for practice and education

1. Providers of palliative care service including hospices should understand the importance of place bonding in offering services to children and parents:

Appreciating the dimensions of place familiarity, place identity, place belongingness, place association and place rootedness should enable providers of children's hospices and palliative care services to understand the complexities and nuances of the decision making process for parents. Services should be presented in a way that acknowledges the importance of place bonding for parents and as such instils confidence that their child will be cared for in the manner that they seek.

2. Health care professionals and carers should work in teams and have identified children allocated to their team:

This means that parents will be able to identify and liaise with named individuals to offer reassurance that the staff/carer has the sufficient knowledge and skills to care for their child in the manner that they aspire to. This will also mean that there is continuity and consistency in care, relationships are established and trust built between parents, child and staff/carer.

3. Fostering place belongingness through education and training:

Specific trainings strategies should be put in place to ensure that staff have the skills and competencies to work with the children in their team. Staff and carers should reflect on and foster many of the characteristics that parents require for a sense of belongingness to be present in the hospice. Adopting the concept of place bonding as an underlying philosophy of care for service development within the hospice should be explored. Additionally there must be more training and education for health and social care professionals locally to raise awareness of the services which provide palliative care. Consequently they can then feed this information forward to parents of children with life-limiting and life-threatening conditions.

4. Hospice services could benefit from reflecting aspects of place bonding within their branding and marketing information:

Hospices should seek to reach more

parents and their children with life-limiting conditions living in their community. If hospice care is to be more accessible, hospices must work closely with other services and find ways to encourage parents to overcome their concerns about accessing hospice services. Hospices need to be explicit in what they do and the services they provide. Adopting the model of place bonding into service literature and websites has the potential to affect parents' preconceptions of hospice care. This also includes clearer signposting for parents in terms of respite services offered at the hospice. Earlier recognition and engagement with children, young people with life-limiting conditions and their parents will enable families to understand the services that are offered in the region. It is proposed that staff at the hospice work closely with community nursing teams, creating a hospice presence and enabling families to benefit from the hospice expertise and learn more about the services that the hospice provides. Offering support groups and family fun days in different areas throughout the region will foster relationship building between staff at the hospice, parents and other service providers.

5. Challenge, review and revise the existing model for respite within the hospice for cognitively able teenagers and young adults: The respite needs for teenagers who are cognitively able do not seem to be being met and more careful consideration of their developmental needs, independence and social needs should be accounted for. In particular the needs of boys with Duchenne muscular dystrophy should be addressed.

6. Children's hospices should engage with local adult services to lead the way in coordinating transition for young people with life-limiting conditions. Professionals working in adult services need to reach out to young people to begin a process which encourages the five dimensions of place familiarity, place identity, place belongingness, place association and place rootedness are focused on young people and their parents. By doing so young people and their parents who are transitioning to adult places of respite can begin to get to know staff, a new environment and potentially a new approach to care.

8.4.2 Recommendations for policy

In addition to recommendations specifically for practice and education at Woodlands, the co-sponsor of this thesis, there are wider implications for policy and future research. At a time when palliative care and end of life care services are under the scrutiny of the Care

Quality Commission, a palliative care currency is being introduced, there is an increasing demand for efficiency and effectiveness against increasing financial constraints for fund raising, hospices are in a position where they must continue to find ways of providing safe, compassionate and high-quality care to meet the needs of their local population. The findings of this study suggest that the following should be considered by policy makers:

1. Implementation of the place bonding model developed in this study into respite services: There is scope for other children's hospices and services which offer respite to explore this model of place bonding. The 'journey' of parents with life-limiting conditions is influenced by many factors. It is suggested that by adopting an approach to care that models the five dimensions of place bonding, and adopts the characteristics described within the place bonding model in other services, the same sense of 'a respite service that gets it right' for parents of children with life-limiting conditions can be achieved.

2. Provision and delivery of respite services for young people with life-limiting to transition into adult services: As children with life-limiting conditions survive longer and transition into adult services a more thorough understanding of the sensitivities and nuances of decision making for parents may encourage a more manageable transition. In particular commissioners and providers of services should consider the provision of developmentally appropriate services for young people who, although chronologically ready for transition are not cognitively ready for current adult hospice settings. It is suggested that the model of place bonding presented in this study should form the basis for healthcare commissioners and service providers to consider, reflect upon and gain a better understanding of the needs, the characteristics and the environments that better cater for the needs of young people with life-limiting and life-threatening conditions and their families. Providers of adult services should consider providing services that reflect the characteristics that parents require for respite services for young adults with life-limiting conditions.

3. Provision of appropriate respite services and facilities for young men with Duchenne muscular dystrophy: The findings of this study have demonstrated that these young men require a different model of respite from that which is provided by the hospice. Services should be commissioned to reflect the need for peer support, to encourage

independence and the development of adult skills. Additionally, staff will need education and training specifically to address the needs of this group of young people. When planning facilities and there should be an awareness of and adoption of the place bonding model.

8.4.3 Suggestions for further research

This study has highlighted a number of areas for future research:

The sample in this study was predominantly White British and therefore there was a lack of diversity in regards to ethnicity. Further work which develops insight into the characteristics necessary for parents from different cultural backgrounds to develop affective bonds with places should be considered.

Participants in the study were parents of children with life-limiting conditions. Giving parents the opportunity to share their experiences of hospice and palliative care services is fundamental for service development in this area. However, further work with children and young people at the hospice particularly those teenagers who are cognitively able would enable comparisons with parents' perspectives and determine the needs of this group of young people are considered and exploration of whether the hospice is the right place for respite for them.

The theory of place bonding at the hospice developed from the findings of this study could be investigated further by researching collaboratively with other children's hospices and other respite services for children with life-limiting conditions. Whilst this study has identified the five dimensions of place bonding, understanding which, if any of the five dimensions is more important for creating a sense of rootedness for parents could be explored further. In particular the model of place bonding could be used to guide questions about place experiences in settings involved in the transition of young adults.

Research should be undertaken to explore staff and carers' perceptions and experiences of the five dimensions to examine whether these have an impact on the way they generate (or not) place bonding for parents and children.

8.4.4 Dissemination of the findings

Dissemination of the findings of the study will be achieved in a number of ways. Throughout the course of this study there has been regular feedback with the Board of Trustees at the hospice. A final presentation to the Board is scheduled for 5th December 2016, followed by staff at the hospice. Following this a short written summary of the research findings will be provided to the parents who participated in the study. Wider dissemination of the results will be available for parents who did not participate on the hospice website. Presentation of findings will also be given to the community services who acted as participant recruitment centres for the study. Anonymity will be maintained throughout all of these presentations and PIC's will not be identified individually.

Upon final completion of the thesis the findings will then be shared across the wider professional and academic community. This will include submission of papers for presentation at children's nursing and palliative care conferences nationally and internationally. Academic papers will also be prepared for submission to various nursing, palliative care and research journals, focusing on various aspects of the study. Whilst dissemination of the findings of this study is important it is also imperative that the recommendations for practice, service development and future study are considered and as appropriate, implemented.

8.5 Conclusion and closing comments

It is clear that demographics of this population of children is changing and more children with life-limiting conditions are surviving longer. To manage this increase in numbers of children, children's hospice services now need to re-think their provision, adopting a model which delivers respite care in response to the needs of parents and children with life-limiting conditions. However, to do so they must understand the needs of the communities they serve. Woodlands sponsored this PhD because they wanted to learn more about the needs and experiences of the families in their local community. If palliative care services and hospices are to develop services that are meaningful they must find ways to hear what children and their families want. As I reach the end of this thesis and reflect on my research journey I come to the conclusion that despite the difficulties in recruiting to studies in palliative care the lessons to be learnt from the experiences of parents of children with life-limiting conditions and their families are vital and must be

pursued. Additionally, hospices need to work in partnership with their local stakeholders to consider their future direction and define the services that they will deliver.

Using a constructivist grounded theory approach a theory of place bonding was proposed which offered new insights into the journey that parents take as they decide whether or not to accept help in caring for their child with a life-limiting condition. Five dimensions of place bonding are described which culminate in a sense of rootedness and attachment to the hospice. When present the five dimensions: place familiarity, place identity, place belongingness, place association and place rootedness led parents to a sense that they had found in the hospice a place where they felt at 'home' and a place where they believed their child would be well cared for.

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Appendices

Appendix 1.

Summary of the methodological key features, key findings and limitations of the articles retained from the literature search and included in the narrative review

Author, Year of Publication Country of study	Aim, Design and methods	Key findings pertinent to this study	Theme	Limitation of paper reviewed
Bergstraesser et al. (2013) USA, UK, Canada, Switzerland, N. Zealand	Qualitative study to develop a screening instrument for paediatricians that would improve timely identification of children who would benefit from palliative care. Semi structured interviews of experts from 4 countries (n=7), focus groups discussions (n=11).	Initial development phase of a tool which could be used to identify children with palliative care needs. Five domains highlighted with questions and scored for each domain.	Identification of children with palliative care needs	Initial Data collected 2008. Methods used only assessed face and content validity of tool from perspective of health care professionals, tool not trialled with patients. Focus group single site only.
Bergstraesser et al. (2014) USA, UK, Canada, Switzerland, N. Zealand	Second stage of validity testing of Paediatric Palliative Screening Scale. Online questionnaires - palliative care experts (n=33) from Europe, US, Canada, Australia, N Zealand. Used case vignettes and asked participants to assess the need for palliative care on a 7 point Likert scale. Regression analysis used to weight attributes in terms of importance.	This study validates indicators which reflect palliative care needs of children and their families. Emphasis on the need to identify children.	Identification of children with palliative care needs	Case vignettes or attributes of tool not identified in the article. Not clear how weightings were attributed –supplemental material identified as available online could not be found. Case vignettes do not always mirror real situations, no testing of tool with patients.
Bradford et al. (2012) Australia, Queensland	Stakeholder event/focus groups of HCP's (n=60) to identify barriers and gaps in services for children in Queensland with life limiting conditions to inform a future model of care.	Identified barriers - equity in access to services; awareness, understanding and fear associated with this work; experience of health professionals; funding and resources. A lack of respite options, the need for further education, improved collaboration and improved communication between services were identified as existing gaps.	Barriers and gaps in service provision	Participants limited to South East Queensland only. Results of study specific to SEQ. Prior to focus group discussions there were several presentations which may have biased results.
Champagne & Mongeau, (2012) Quebec, Canada	Parents' perspectives of respite services offered at a children's hospice. Semi-structured interviews with mothers (n=25) and fathers (n=8).	Respite offers parents rest, freedom from care responsibility, Also positive affect on siblings.	Parent's perception of hospice / Respite	One hospice in Canada. In seven of the interviews both parents interviewed together. Primarily mothers views. Little diversity in sample characteristics .
Cooney & Atwood (2013) UK	Study by Wiltshire PCT to gather feedback from parents of children who eligible to use one of 3 hospices in area. Also non-hospice users. Semi structured interviews via telephone and email with parents (n=12).	Unable to recruit non hospice users. Parents described battle to access services. Access and referral routes to hospices not clear. Hospice provision described as true respite.	Parent's perception of hospice	Obvious gatekeeping by PCT and hospice team affected recruitment. Interviews conducted by telephone and e-mail.
Davies et al. (2004) Canada	Evaluation project of the respite component offered by hospice in Vancouver. Face to face interviews with 18 families (n=50) to develop questions for subsequent questionnaire to families (n=144).	Benefits of respite care at hospice described.	Respite at hospice	Retrospective evaluation from parents who had used hospice when it first opened 1995-1998, no date when survey took place. No demographic information available on participants. No information available on results of face to face interviews which informed questionnaire. No other palliative care programme available at time in Vancouver. Response rate 45% to survey.

Author, Year of Publication Country of study	Aim, Design and methods	Key findings pertinent to this study	Theme	Limitation of paper reviewed
Davies et al. (2008) USA, San Francisco	Exploration of barriers to palliative care experienced by HCP's in one Children's hospital. Questionnaire survey re. HCP perspective on paediatric end of life care (n=240). Questioned on 26 barriers identified from literature and clinical experience of authors.	Identified barriers to palliative care uptake - difficulty with uncertain prognosis, family not ready to acknowledge incurable condition, time restraints and language barrier.	Barriers to palliative care	Single site USA study – tertiary care hospital. Data collected 2002, questionnaire used not available, bias in barriers identified by authors. Only reported doctors and nurses responses (n=198). Terminology used focused on end of life care.
Eaton (2008)	Exploration of the experiences of families, whose children have LLC and complex healthcare needs, of receiving respite care at home or in a hospice. Semi-structured interviews with families (n=11).	Areas of concern identified as significant to families were referral to respite service, service organisation, communication, relinquishing control to respite carers and satisfaction with service.	Respite	Paper reports part of a larger study across Wales looking at the quality of care for children in the community. Sample was a convenience sample, a subgroup of 27 families receiving care from community children's services and also respite at home or hospice. Gatekeeping by senior nurses as to which families to be interviewed-bias. Limited demographic information regarding the sample.
Fadul et al. (2009) USA, Texas	Web based survey of providers of palliative care, oncologists and other HCP's (advanced practice nurses and physician assistants) (n=140). Test the hypothesis that the name palliative care compared with the name supportive care has a negative impact on the timeliness of palliative care referrals and secondly the perception of the two names.	Most preferred term supportive care. Palliative care term seen as a barrier to referral, decreasing hope in patients and causing distress to families.	Terminology	Amongst HCP's working in single site cancer centre in USA. Although not specific assumption is HCP's working primarily with adult patients with cancer.
Feudtner et al. (2010) USA, Philadelphia	Prospective cohort study to test the hypothesis that parental hope, along with parental perceptions of the trajectory of the child's health would be associated with their decision to enact an LOI order (limit of intervention) during the 6 months after entry into the cohort. Parents of children receiving palliative care (n=43). Used tools - Hope Scale and Affect scale to score patterns of hope and decision making.	The findings of this study underscore the importance of affect and patterns of hopeful thinking in the processes of decision making when confronting serious illness and strongly suggest the need for clinicians to be aware of and respond to these influences. Awareness of this may be important and related to uptake of PPC services.	Barriers to palliative care	Single site children's hospital in USA. Only followed up patients six months after entering cohort. Hope scale tool used validated in adults.
Feudtner et al. (2011) USA	Multicentre prospective cohort study over a 3 month period from 6 PPC teams in US and Canada, exploring all PPC consultations (n=515) and 12 month follow up. Description of demographic and clinical observations and outcomes of children receiving hospital based PPP in US.	Increasing survival rates demonstrated in US, congenital/genetic conditions highest followed by neuromuscular conditions, then cancers.	Epidemiological data	Data was collected retrospectively from medical records only, therefore accuracy issues. Outcome measurement was based on survival rates or place of death, there was no measurement of impact of services provided on families.

Author, Year of Publication Country of study	Aim, Design and methods	Key findings pertinent to this study	Theme	Limitation of paper reviewed
Fraser et al. (2011b) UK	Epidemiological study to identify the prevalence of children, 0-19 yrs. with life-limiting conditions 2000-2010 for England, Scotland, Wales and Northern Ireland. Examined hospital episode statistics, categorised diagnoses using an adapted ICD-10 coding within four independent inpatient hospital datasets.	Prevalence per 10 000 population (0-19 years) was calculated by age, diagnostic group, ethnicity and deprivation within each country for each year (from 2000/01-2009/10). England identified prevalence had increased over ten years from 25 to 32/10 000. Total of just over 40 000 children with LLI in England. Highest prevalence in under 1 yrs. due to congenital anomalies. Rising prevalence in 16-19 yr. age group. Prevalence data available per geographical region.	Epidemiological data and identification of children	Prevalence estimates are dependent on identification, only children with hospital admission in the ten years were included. Reliant on accuracy of collection and reporting of hospital episode data.
Fraser et al. (2013) UK	Epidemiological study to identify the prevalence of young adults 18-40 yrs. with life-limiting conditions living in England 2000-2010 Same methodology as above study.	Separate data of prevalence in 18-25 yr. group presented. Increase in number of children surviving into adulthood.	Epidemiological data and identification of children	Prevalence estimates are dependent on identification, only adults with hospital admission in the ten years were included. Reliant on accuracy of collection and reporting of hospital episode data.
Hain (2005) UK	Data capture from surveillance and reporting mechanism in Wales to establish prevalence of children needing palliative care in Wales,	226 children identified across Wales, prevalence 3.75/10 000. Hain concluded that this was underestimation. Highlighted the need for further epidemiological studies to be conducted.	Epidemiological data and identification of children	Only those children who were known to a paediatrician, one of the two hospices or the specialist PPC service identified. Definition of palliative care not detailed. Only children in Wales.
Hain et al. (2013) UK	Development and piloting of a tool to define the group of conditions that are LLI in children. Mapping of diagnoses from patients at five hospices and one tertiary palliative medicine service. ICD-10 codes applied to each diagnosis. Directory piloted by exploring death certificate data over a 5 year period 2002-2007.	Over 300 codes identified – demonstrating the diversity in diagnoses. Can be used to define population of children requiring palliative care. Can be used to analyse epidemiological data. Can be used to underpin criteria for entry and referral to hospices.	Epidemiological data and identification of children	Directory formed from 5 hospices – no information known of size of populations of children in the hospices. No way of knowing if all diagnoses included.
Harrop & Edwards (2013) UK	Best practice article to clarify the role of specialist paediatric palliative care, identify who should be eligible for such care, describe the services available and describe a tool for assessing some of the most challenging referrals.	Review article of research to date in UK and current models of service delivery. Description of a tool which is used by one hospice group of clinicians to identify vulnerability in children within Category 4 of ACT/RCPCH. Highlighted the importance of the need for development of tools to enable clinicians to identify palliative care needs and then refer to services.	Identification of children for referral	Limited evidence of how tool was developed. Validation information not available but appears to have been used over a two year period at hospice in Oxford.

Author, Year of Publication Country of study	Aim, Design and methods	Key findings pertinent to this study	Theme	Limitation of paper reviewed
Hunt et al. (2013) UK	The Big Study. Exploration of the needs of children with LLC and their families living in the West Midlands. Five strands to the project: Strand 1: Surveys and geographic analysis: Identifying the prevalence of need • Strand 2: Understanding the met and unmet needs of children and families • Strand 3: Understanding how professional networks support services • Strand 4: Economics and costing: Exploring the costs of care to providers and families • Strand 5: Facilitating the involvement of parents, carers and young people.	Strand 2, appreciative inquiry approach, in-depth interviews and art based focus groups, 41 parents and 18 children participated. Many needs met, unmet needs – families under pressure, services under pressure. Study highlighted the importance of taking into account what children, young people and families need so that informed service improvements can be made.	Needs of Parents of children with LLC	Multi-phase study commissioned by national charity for children with LLC. Study findings available in report style format, with limited in-depth information regarding each strand.
Inglin et al. (2011) Switzerland	Qualitative study to explore the perceptions and needs of families caring for a child with a LLC. Parents interviewed (n=15), three groups, cancer patients, neurological and non-cancer/non-neurological.	Little desire for hospice provision in Switzerland, prefer care at home. PPC is undeveloped in Switzerland compared to other European countries. Focused on need for psychosocial support.	Needs of Parents of children with LLC	Small sample size. Interviews only conducted in German speaking side of Switzerland. Interviews were with mothers only. Very different health care delivery system in Switzerland compared to UK.
Junger et al. (2010) Germany	Survey of general paediatricians (n=293) to examine barriers to paediatric palliative care in Germany. Interviews with paediatricians (n=5) to inform development of questionnaire.	Identified barriers - time restrictions, lack of reimbursement, lack of support for professional. Felt better if more supported by colleagues, spec services and nursing services. 43% experiences was from children with cancer diagnosis.	Barriers to palliative care	Different model of Delivery of PPC in Germany. Experience amongst paediatricians primarily with children with cancer - limited experience with other conditions of children with LLI may have biased results.
Kirk & Pritchard (2012) UK	The aim of the study was to investigate parents' and young people's perceptions of hospice support and identify how support could be improved. A mixed-method approach was used involving a postal survey of families and in-depth qualitative interviews with a purposively sampled subsample of parents and young people.	Detailed quantitative data of parents views of hospice support. Identified need to develop support for teenagers. Viewed hospice as 'safe hands', Parents valued break from caring. Hospice was a place where support to whole family offered.	Parent's perspectives of hospice support	Response rate to questionnaire was 50%, no information on non-responders. Single hospice site in UK.
Kanpp et al. (2009a) USA, Florida and California	Survey of paediatricians (n=303) to assess if they would refer children to palliative care and at what point in their illness across five given trajectories of conditions. Across two states in USA.	Demonstrated that most paediatricians would refer but differences across five trajectories of when and also differences with experience of doctor.	Referral criteria	Across two states USA where structure of hospice palliative care is different, difference for profit and non-profit organisations. 44% response rate of paediatricians across two states. Only assessed criteria for referral based on five illness trajectory, no other factors included.

Author, Year of Publication Country of study	Aim, Design and methods	Key findings pertinent to this study	Theme	Limitation of paper reviewed
Knapp et al. (2009b)	To estimate nurses' knowledge of palliative care (n=279) using two palliative care quizzes: the palliative care quiz for nursing (PCQN), and a quiz developed by Ogle et al (2002) to measure knowledge about hospice policies and services.	Based on questions asked nurses' knowledge was good. Examples of questions asked are included in article.	Nurses knowledge of palliative care	One site in Florida. Inconsistencies in numbers reported in demographics of participants. Do not total 279 in all areas. Response rate 61%, all nurses surveyed worked in specialist area of children with complex health needs may bias results. Tools used to measure knowledge validated only for adult palliative care use.
Knapp et al. (2011a) USA, Florida	Cross sectional design, using online and mail-in survey data with paediatric nurses (n=279) to assess the attitudes toward hospice and palliative care. Same study/sample group as (2009b) study above.	Bivariate results showed there were significant differences between the attitudes of nurses employed where there was a PPC programme. Training and education in PPC has potential to alter attitudes, effect of increased referrals and better outcomes for families. Delivery of PPC in USA different but in Florida the six month reimbursement fee has been waived.	Attitudes to palliative care	Limitations as identified in (2009b) article. Tool used to measure attitudes adapted from adult tool and statements developed from authors - seven negative statements as opposed to four positive - potential for bias.
Knapp and Thompson (2012) USA, Florida and California	Cross sectional survey of paediatricians (n=303) to describe the barriers to PPC and associated factors across two states in USA.	Themes identified - families' reluctance to accept palliative care, families viewing palliative care as giving up. 40% of paediatricians indicated that associating hospice with death was not a barrier.	Barriers to palliative care	Only two states in USA included. 44% response rate with no information on non-responders. Survey used included 15 pre-identified barriers adapted from adult study, potential for bias.
MacDonald and Callery (2004) UK	Exploratory study to define how respite is defined by parents, nurses and social workers responsible for the care of children with complex needs. In-depth interviews, participant observation and document review with mothers (n=19), fathers (n=7), nurses (n=13) and social workers (n=4) from across three counties in NW England.	Parents defined three categories of respite. Differences noted between parents and social workers perception and value of respite provision. Parents valued feeling of being normal family if child in respite.	Respite	Small sample, not necessarily representative of parents with children with complex needs. Inclusion criteria were children with special needs – information re diagnoses not included, wide variation in definitions. May or may not be representative of children with palliative care needs.
Martin House Children's Hospice Report (2013) UK	Three phase multi method project to understand regional provision of palliative care across Humber and Yorkshire. Phase 1 interviews 25 experts, one focus group with 8 young people, literature review to aid understanding of palliative care, barriers to care. Phase 2 mapping exercise of service provision regionally. Phase 3 interviews with 24 parents, 4 young people and 19 staff.	Difficulty in identifying services available in the region. Barriers to access included differing referral criteria, funding restrictions. Difficulties in identifying which children to refer for palliative care. Lack of out of office hours provision. Parents identified need for respite and a break from care. Fears about transition.	Provision of PPC services	One region in England. Mapping of services – no way of knowing if all services included.

Author, Year of Publication Country of study	Aim, Design and methods	Key findings pertinent to this study	Theme	Limitation of paper reviewed
Melvin and Oldham (2009) Australia	Phenomenological study in Perth, to determine the barriers to timely referral to palliative care services and the effect of late referrals on quality of life. Health care professionals working in the palliative care field interviewed (n=11).	Identified four themes which affected referral as lack of knowledge, fear of losing control, feeling a failure, fear of negative impact of a referral on families.	Barriers to PPC	Region of Perth In W. Australia. Participants all knowledgeable in field of PPC, views of professional not working in field not included. Not clear whether experiences was in adult, children or both.
Monterosso et al. (2007) Australia	Two phase design, mixed method study, phase 1 questionnaire and phase 2, follow up semi-structured interviews. Participants - parents (n=134) and also service providers (n=20). Looking at service provision in West Australia and barriers and facilitation factors associated with palliative and supportive care.	Demonstrated that families wanted better communication, financial help, better access and availability to respite services, skilled carers. Difference found between cancer group (n=19) and non-cancer (n=110) patients. Parents in non-cancer group wanted help maintaining a normal lifestyle.	Needs of families	2003-2005. Study in Western Australia where there were no hospice facilities available so palliative care services not include these facilities. Significant difference between sample size of parent groups in phase 1. Parents in cancer group were all bereaved therefore making their perception of their needs very different.
Miyashita et al., (2008) Japan	Semi-structured interviews to explore barriers to referral to inpatient palliative care units. Participants, (n=63) including 13 advanced cancer patients, 10 family members, 20 physicians, and 20 nurses in palliative care and acute care cancer settings from five regional cancer institutes in Japan.	There was a negative image to term palliative care and therefore was a barrier to early patient referral. Associated palliative care with ending curative treatments like cancer treatment.	Barriers to palliative care	Study in Japan. Participants experienced primarily in cancer. No way of knowing if experience was adults, children or both.
Morstad Boldt et al. (2006) USA	To assess parents' and health care providers' perceptions of the name and description of a paediatric palliative care (PPC) program. Randomised parallel survey across 3 paediatric health care sites, parent (n=105) and staff (n=79) asked if they would use a PPC programme and their understanding and feelings about this.	Found that initially, parents were more likely to use a program if it was called supportive care versus palliative care, a difference that disappeared after parents read a nonthreatening program description. Lack of understanding re palliative care. The term palliative care is associated with negative feelings.	Terminology	Parents were recruited from areas like intensive care and general paediatrics where there child may not have had a life-limiting or threatening condition so their knowledge and understanding of palliative care terminology may have been very limited, biasing the results.
Noyes et al. (2013) UK	Multi-phase, mixed methods epidemiological and economic study carried out across North Wales, to estimate numbers of children under 19 yrs. with Life-limiting conditions, cost services, determine child/parent preferences and cost of end of life care at home.	Identified challenge for researchers in producing data that is precise and of practical use, difficulty in estimating numbers of children with LLI. Highlighted difficulty in assessing needs and determining costs of service provision.	Epidemiological data and identification of children	Across North Wales only. Article focused on information specifically for commissioning purposes.
Ogle et al. (2002) USA	Mailed survey to doctors (n=264) to explore their perception of hospice care, attitudes, referrals and knowledge.	Physicians were positive about referrals to hospice care and cited that it was patient and family readiness which was the barrier to early referral.	Barriers to palliative care	One community site in Michigan. No detail if doctor's experience was in adult or children palliative care specifically.

Author, Year of Publication Country of study	Aim, Design and methods	Key findings pertinent to this study	Theme	Limitation of paper reviewed
Steel et al. (2008) Canada	Pilot study to describe the experiences of children and families' transition to a Canadian paediatric hospice. Semi structured interviews with parents (n=8), siblings (n=2), Child with LLC (n=1).	Hospice referral considered when something changed in parents lives – to a critical level of need. Parents not aware of support available at hospice, associated only with end of life care.	Parents perspectives of hospice	Single site hospice in Canada. Small sample, pilot study. Researcher left in middle of study and in early stages of analysis, handed over to another researcher. Parents had very little experience of using hospice prior to interviews.
Thompson et al. (2009) USA, Florida, California	Survey to assess how paediatricians define palliative care, their experiences with actual referrals for palliative care and which diseases paediatricians would refer for palliative care and when they think referrals should occur for 13 different diseases.	Paediatricians were divided in their definitions of palliative care; 41.9% defined it as hospice care, 31.9% offered alternative definitions, and 26.2% did not know. Only 49.3% had ever referred patients to palliative care and 29.4% did not know whether local services existed.	Referral criteria and definition of PPC	Two states in USA where PPC delivered differently in terms of access to PPC services. 40% response rate. Only asked about 13 specific diseases.
Twamley et al.(2013) UK	A cross-sectional survey of HCPs (n=132) working in a paediatric tertiary care hospital with an established paediatric palliative care team, to explore staff perceptions of barriers, knowledge and attitudes, with the aim of developing interventions to increase patient access to palliative care services.	Identified association between palliative care and end of life care with professionals. Perception that parent related factors as most significant barriers	Barriers to palliative care	One paediatric tertiary care hospital in UK. Established paediatric palliative care team may have biased results. Only 14% response rate may have been professionals with existing knowledge.
Whiting (2014a,b) UK	Study to investigate the experiences of parents of children with complex health needs in relation to the help and support they receive when caring for their child. A series of in-depth semi-structured interviews undertaken with the parents of children (n=33) with a disability or complex health need. Families were categorised into one of three subgroups: children with a disability, children with a life-limiting or life-threatening condition, or children with technology dependence.	Second article in series demonstrated that the greatest area of unmet need is in the provision of planned and regular breaks from caring, including regular overnight out-of-home respite and the opportunity for other members of the family to have the time to socialise and take leisure breaks. Third article talked about battle ground for parents.	Needs of families	Study conducted in one county in England. Focus of study was on children with complex needs and disabilities rather than palliative care. No identification of specific sample numbers for each group, possible overlap amongst all three subgroups.
Wood et al. (2010) UK	Study to collect qualitative experiential data to identify the events that families of children with a LLC see as major markers of their child's progression in the four ACT categories. A further aim of the study was to gather descriptive data about the experiences of families caring for children in all four ACT/RCPCH categories. Parents (n=26) from four ACT categories – semi structured interviews ACT 1,2,3,4 (n=4, 3, 7, 12 respectively).	Parents identified 34 milestones falling into five phases of trajectory - diagnosis, loss of normality, adjusting to new normality, palliative phase and death. Four descriptive themes were uncovered that ran through the milestones: development of expertise, battles around healthcare provision, information giving and relationship with professionals. Confirmation that ACT categories useful for identification of children with LLC.	Categorisation of LLC Experiences of parents	Study participants from South Wales only – area where very poor PPC services at the time of study. Underrepresentation in categories 1 and 2.

Appendix 2.

Participant Information Sheet Phase 1

Participant Information Sheet**Study Title: Children's Hospice Provision in the * [region] Phase 1****Researcher: Helena Dunbar**

You are being invited to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it will involve. Please read this information carefully and feel free to discuss it with your family and friends. If there is something that is not clear or you want more information, please ask. Taking part in this research is entirely voluntary and will be confidential.

Why am I being invited to take part?

You are being invited to take part because you have a child who uses some of the services that * offers. Other families that you may know may also have been invited to take part in the study.

What is the study all about?

The purpose of the study is to find out what families want and value from hospice and palliative care services available throughout the region.

What would I have to do?

If you are willing to take part in the study you will be asked to attend a group with up to seven other parents who also use * and myself, (Helena Dunbar), the researcher and a research assistant, from De Montfort University. I will be asking you and the other parents in the group your opinions about hospice and palliative care services. I am interested in everyone's ideas. With your permission I would like to audio-record the discussions. The group meeting will last up to two hours. I will be running several groups throughout the region and you will be able to choose a group which is most convenient for you to attend. Travel expenses will be agreed with me and you will be reimbursed. If required child care can be provided for your child/ren.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw from the study at any time and without giving a reason. However dependent on the time that you withdraw from the study it may not be possible to remove the information that you have supplied. If you decide not to take part please feel free to keep this information sheet and be assured that this will not affect the care that you and your child receives at *.

What are the possible disadvantages and risks of taking part?

Sometimes talking about the care your child needs can be upsetting. However, you will never be under any pressure to answer questions or talk about topics that you prefer not to discuss. You can stop or take a break at any time. I am a registered nurse very experienced in caring for children with complex medical needs. I will be able to provide you with contact details of support services

Enclosure Number 2 Participant Information Sheet Phase 1 Vs. 3, 15th June 2014*Children's Hospice Provision*

Page 1



available should you feel that you need to talk to someone following the focus group. If you agree, I will also ring you 2 days after the focus group to see how you are.

What are the possible benefits of taking part?

There are no direct benefits for you if you take part in the study although sometimes families say it helps to share their ideas and talk in a group. This can be helpful and some people enjoy the opportunity to reflect, that research participation sometimes offers.

Will my taking part in the study be kept confidential?

I am independent of * Hospice and as such anything you say will be kept in the strictest confidence. Some quotes from the interviews will be used in the thesis and final report of the research and in articles and presentations. However, your name or details that will identify you or any other person will not be used in anything that we write or in any presentation that we make. We will not be informing anyone else that you are taking part in the research.

If matters arise during the course of discussions which give rise to specific professional concerns e.g., bad practice, I will discuss the matter with you at the end of the focus group. It will be necessary for me to discuss the matter with my supervisors and we will make a decision as to how this may be addressed. You will be kept fully informed of any actions that may need to be taken by myself or my supervisor as a result of your disclosure.

Procedures for handling, processing, storage and destruction of study data meet the requirements of the Data Protection Act 2003. We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the study, the data collected for the study will be looked at by authorised persons from De Montfort University who sponsor the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the University will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Any personal data (address, telephone number) will be kept for 6 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 10 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Who is organising and funding the research?

The project is a partnership between De Montfort University and * Hospice for Children and Young People. Whilst * is the main hospice in this study we recognise that there are others available within the area that you may also use and wish to talk about. Professors Jayne Brown and Bernie Carter together with a steering group of experts in palliative care will be overseeing the conduct of the



study. The study has been reviewed and approved by De Montfort University Faculty of Health & Life Sciences Research Ethics Committee, the Clinical Governance Committee at * Hospice and(insert REC committee and approval number).

What happens if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected up to that point may not be able to be erased and this information may still be used in the project analysis.

Involvement of the General Practitioner/Family doctor (GP)

We will not be involving your GP. We will not be informing your GP of your involvement in the study

What will happen to the results of the research study?

This study is part of my PhD. The results will be submitted for publication in healthcare journals and be presented at various conferences. An executive summary will be made available on the website of Rainbows Hospice for participants or if you prefer I can send you a copy. The findings of the study will be considered in the future development of services across the region.

What if something goes wrong? / Who can I complain to?

During the study if you are not happy about something please speak to me about it. Following this if you are not satisfied with the outcome please contact Professor Jayne Brown, Academic Supervisor for the study, jbrown@dmu.ac.uk or the Administrator for the Faculty Research Ethics Committee, Research and Commercial office room 1.25, Edith Murphy House, De Montfort University, Leicester, LE1 9BH or hlsfro@dmu.ac.uk

What happens now?

If you would like to take part in the study or find out more about it please contact me (Helena Dunbar) either by phone, e-mail using the information given below or complete and return the reply slip with details of the best way to contact you. A stamped addressed envelope is included.

Thank you for taking the time to read this information.

Helena Dunbar Tel 01509 638012 helena.dunbar@...co.uk

Tel 0116 201 3830 hdunbar@dmu.ac.uk

I would like to be involved in a focus group for the study, **Children's Hospice Care Provision in the * [region]**

Please contact me by



Telephone (please detail best number to get hold of you)or

E-mail (please include e mail address)

Name

Signature.....

Date

Appendix 3.

Participant Information Sheet Phase 2



Participant Information Sheet

Study Title: Children's Hospice Provision in the * [region] Phase 2

Researcher: Helena Dunbar

You are being invited to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it will involve. Please read this information carefully and feel free to discuss it with your family or friends. If there is something that is not clear or you want more information, please ask. Taking part in this research is entirely voluntary and will be confidential.

Why am I being invited to take part?

You are being invited to take part because you have been identified as someone whose child may benefit from additional services and whose experiences might help shape ideas for future service development for children with complex needs living in the *

What is the study all about?

We want to explore and identify the types and characteristics of services that parents may or may not want when caring for their child.

What would I have to do?

If you are willing to take part in the study you will be asked to take part in an interview conducted by myself (Helena Dunbar); the researcher. You can choose a convenient time for yourself and/or your partner to be interviewed. The interview can either take place at home or at * Hospice. If you decide to be interviewed at the hospice we will cover your travel expenses to the hospice and child care will be available should you need it. The interview will take 60-90 mins and will be digitally audio-recorded.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw from the study at any time and without giving a reason. However dependent on the time that you withdraw from the study it may not be possible to remove the information that you have supplied from the study.

If you decide not to take part please feel free to keep this information sheet and be assured that this will not affect the care that you and your child receives.

What are the possible disadvantages and risks of taking part?

Sometimes talking about the care your child needs can be upsetting. However, you will never be under any pressure to answer questions or talk about topics that you prefer not to discuss. You can

Enclosure Number 5 Participant Information Sheet Phase 2 Vs. 4, 15th June 2014

Children's Hospice Provision

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stop or take a break at any time. I am a registered nurse very experienced in caring for children with complex medical needs. I will be able to provide you with contact details of support services available should you feel that you need to talk to someone following the interview. If you agree, I will also ring you 2 days after the interview to see how you are.

What are the possible benefits of taking part?

There are no direct benefits for you if you take part in the study. However the discussion during the interview allows you to spend time in sharing your experiences. This can be helpful and some people enjoy the opportunity to reflect, that research participation sometimes offers.

Will my taking part in the study be kept confidential?

Some quotes from the interviews will be used in the thesis and final report of the research and in articles and presentations. However, your name or details that will identify you or any other person will not be used in anything that we write or in any presentation that we make. We will not be informing anyone else that you are taking part in the research.

If matters arise during the course of discussions which give rise to specific professional concerns e.g., bad practice, I will discuss the matter with you at the end of the interview. It will be necessary for me to discuss the matter with my supervisors and we will make a decision as to how this may be addressed. You will be kept fully informed of any actions that may need to be taken by myself or my supervisor as a result of your disclosure.

Procedures for handling, processing, storage and destruction of study data meet the requirements of the Data Protection Act 2003. We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the study, the data collected for the study will be looked at by authorised persons from De Montfort University who sponsor the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the University will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Any personal data (address, telephone number) will be kept for 6 months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 10 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.



Who is organising and funding the research?

The project is a partnership between De Montfort University and * Hospice for Children and Young People. Whilst * is the main hospice in this study we recognise that there are others available within the area that you may also use and wish to talk about. Professors Jayne Brown and Bernie Carter together with a steering group of experts in palliative care will be overseeing the conduct of the study. The study has been reviewed and approved by De Montfort University Faculty of Health & Life Sciences Research Ethics Committee and * [REC committee and approval number].

What happens if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected up to that point may not be able to be erased and this information may still be used in the project analysis.

Involvement of the General Practitioner/Family doctor (GP)

We will not be involving your GP. We will not be informing your GP of your involvement in the study

What will happen to the results of the research study?

This study is part of my PhD. The results will be submitted for publication in healthcare journals and be presented at various conferences. An executive summary will be made available on the website of * Hospice for participants or if you prefer I can send you a paper copy. The findings of the study will be considered in the future development of services across the region.

What if something goes wrong? / Who can I complain to?

During the study if you are not happy about something please speak to me about it. Following this if you are not satisfied with the outcome please contact Professor Jayne Brown, Academic Supervisor for the study, jbrown@dmu.ac.uk or the Administrator for the Faculty Research Ethics Committee, Research and Commercial office room 1.25, Edith Murphy House, De Montfort University, Leicester, LE1 9BH or hlsfro@dmu.ac.uk

What happens now?

If you would like to take part in the study or find out more about it please contact me (Helena Dunbar) either by phone, e-mail using the information given below or complete and return the reply slip with details of the best way to contact you. A stamped addressed envelope is included.

Thank you for taking the time to read this information.

Helena Dunbar Tel 01509 638012 helena.dunbar@dmu.ac.uk

Tel 0116 201 3830 hdunbar@dmu.ac.uk

Enclosure Number 5 Participant Information Sheet Phase 2 Vs. 4, 15th June 2014

Children's Hospice Provision

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I would like to be interviewed for the study, **Children's Hospice Care Provision in the * [region]**

Please contact me by

Telephone (please detail best number to get hold of you)or

E-mail (please include e mail address)

Name

Signature.....

Date

Appendix 4.

Invitation Letter Phase 1



Hospice Logo

Children's Hospice Provision in the * [region]

Dear parent

My name is Helena Dunbar. I am a Senior Lecturer at De Montfort University and a children nurse with over twenty years' experience in working with children with complex needs and their families.

I am writing to ask you to take part in a research study carried out in partnership with De Montfort University, Leicester and * Hospice for Children and Young People. In order to plan and develop hospice and palliative care services in the future, we would like to ask your opinion about what families want and value from the services currently available in the region.

You are being invited to take part in this study because *, Director of Care at * has identified you as someone who has experience of the hospice.

Please take the time to read the enclosed information sheet. If anything is unclear or if you would like more information please contact me so that we can discuss this further.

Thank you

Helena

Helena Dunbar

PhD Research Student

Tel: 01509 2013830 helena.dunbar@_____.co.uk

Tel: 0116 201 3830 hdunbar@dmu.ac.uk

Enclosure Number 1 Invitation letter Phase 1 Vs. 2, 1st April 2014
Children's Hospice Provision

Appendix 5.

Invitation Letter Phase 2



Children's Hospice Provision in the *[region]

Dear parent

My name is Helena Dunbar. I am a Senior Lecturer at De Montfort University and a children's nurse with over twenty years' experience of working with children with complex needs.

I am writing to ask you to consider taking part in a research study that is being carried out in partnership with De Montfort University, Leicester and * Hospice for Children and Young People. We want to explore and identify the types and characteristics of services that parents may or may not want when caring for their child.

(Insert name of lead professional from collaborating palliative care team)..... has identified you as someone whose child may benefit from additional services and whose experiences might help shape ideas for future service development for children with complex needs living in the East Midlands.(name of team) have sent you this letter, please be assured that no details have been passed to me and I will only know your identity should you choose to reply.

Please take the time to read the enclosed information sheet. If anything is unclear or if you would like more information please contact me so that we can discuss this further.

Thank you

Helena

Helena Dunbar

DMU/ PhD Research Student

Tel: 01509 638012 helena.dunbar@.....co.uk

0116 201 3830 hdunbar@dmu.ac.uk

Enclosure Number 4 Invitation Letter Phase 2 Vs. 2, 15th June 2014
Children's Hospice Provision

Appendix 6.

Consent Form Phase 1

Consent Form

Study Title : Children's Hospice Provision in the * [region] Phase 1

Name of Researcher : Helena Dunbar

Please consider and answer the following points before signing the consent form. Your signature confirms that you are happy to participate in the above named study. Once signed you will receive a copy of this form to keep.

For each statement please insert your **INITIALS** in the box to indicate you agree with it.

1. I confirm that I have read and understood the information sheet, (Phase 1 Vs. 3 Dated 15th June 2014) for the above study. ☐
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
3. I understand that my participation is entirely voluntary and that I am free to withdraw from this study at any time without giving a reason. ☐
4. I understand that the information collected will form part of a PhD study and can be used in articles, publications and presentations at conferences. ☐
5. I understand that all the information collected will be treated as confidential. Direct quotes may be used in anything written or presented as a result of this research but my name or any information that could identify me or my family will not be included. ☐
6. I agree to the focus group being digitally audio-recorded. ☐
7. I agree to a research assistant being present in the focus group to take notes. ☐
8. I understand and give permission for data collected during the study to be transcribed by a typist chosen by the researcher, to be examined by the supervisors for the study, statistician at the university, if necessary. ☐
9. I understand that any information I provide may be downloaded and data stored electronically at De Montfort University by the named researcher. The Data Protection Act will be adhered to. ☐
10. I understand that if a disclosure is made during discussions which give rise to professional concerns then the researcher may have to break confidentiality. This would be discussed with me. ☐
11. I confirm I consent to take part in phase 1 of the study ☐

Print name of participant

Date

Signature

Print name of person taking consent

Date

Signature

Enclosure No.3 Consent Form Phase 1 Vs. 3 15th June 2014
Children's Hospice Provision.

Appendix 7.

Consent Form Phase 2



Consent Form

Study Title : Children's Hospice Provision in the * [region] Phase 2

Researcher : Helena Dunbar

Please consider and answer the following points before signing the consent form. Your signature confirms that you are happy to participate in the above named study. Once signed you will receive a copy of this form to keep.

For each statement please insert your **INITIALS** in the box to indicate you agree with it.

1. I confirm that I have read and understood the information sheet, (Phase 2, Vs. 4 Dated, 15th 2014) for the above study. ☐
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
3. I understand that my participation is entirely voluntary and that I am free to withdraw from this study at any time without giving a reason. ☐
4. I understand that the information collected will form part of a PhD study and can be used in articles, publications and presentations at conferences. ☐
5. I understand that all the information collected will be treated as confidential. Direct quotes may be used in anything written or presented as a result of this research but my name or any information that could identify me or my family will not be included. ☐
6. I agree to the interview being digitally audio-recorded and downloaded data stored electronically at De Montfort University by the named researcher. ☐
7. I understand and give permission for data collected during the study to be transcribed by a typist chosen by the researcher, to be examined by the supervisors for the study, statistician at the university, if necessary. ☐
8. I understand that the information I provide is subject to the Data Protection Act. ☐
9. I understand that if a disclosure is made during discussions which give rise to professional concerns then the researcher may have to break confidentiality. This would be discussed with me. ☐
10. I confirm I consent to take part in phase 2 of the study ☐

Print name of participant

Date

Signature

Print name of person taking consent

Date

Signature

Enclosure No. 6 Consent Form Phase 2 Vs 4 15th June 2014
Children's Hospice Provision

Appendix 8.

Topic Guide Focus Groups Phase 1

Focus Group TOPIC GUIDE

Introduction and Ground rules,

- **speak one at a time, over talk can't be picked up when I am transcribing**
- Please turn off mobiles
- Introduction of self and (assistant)
- Thank participants for taking part
- Length of time for interview , Stop and have a break at any time
- Reassure re confidentiality, consent to record

Background

- Tell me one thing you want us to know about your child
- Describe to me the services you use at * and how long you have been using the hospice
- What other services are you using besides *

Making decisions

- What persuaded you to use hospice? Who referred you ? Timing of referral
- Think back to the first time you came to hospice, First impressions ?
- How can we identify when in a child's journey a referral to hospice should be made?

Hospice characteristics

- How have services at * made a difference to your family, tell me about these? most significant? not so good and why?
- What are the characteristics that you as a family want from hospice
- How would you describe hospice to another family who don't use it
- What makes a hospice different from other service providers

Terminology

- When you hear the words palliative care what comes to mind?
- We often use the words life limiting life threatening what other words would you like us to use when talking about your child's condition.

New Services

- What would make the most difference to your child and family
- What would it look like

Appendix 9.

Topic Guide Semi-Structured Interviews Phase 2

Interviews : TOPIC GUIDE

Study Title : Children's Hospice Provision in the * (region) Phase 2

This aims to provide an overview of the topics to be covered. Questions will be tailored to the individual participant/s.

Introduction

- Introduction of self, Explain purpose of research
- Thank you for taking part, Reassure re confidentiality, consent to record
- length of time for interview, Stop and have a break at any time

Background of child

- Tell me your name, one thing you want me to know about your child, and one thing about your family?
- Cover –
 - Diagnosis, Age, when diagnosed
 - Services that are using in community, hospital
 - Referral process

Making decisions about services to access

- What persuaded you to useservices?
 - Consider factors involved, barriers and facilitators
- Think back over the last few months, year, what has made the most difference to your family, tell me about these?
- What was most significant and why?
- What not so good and why?
- If you could change one thing what would it be and why?

Knowledge and understanding

- When you hear the words palliative care what comes to mind?
- How does that differ do you think from the services that * hospice offer ?
- The word hospice?
- How far away do live from hospice?

Characteristics of services want

- Have you thought about the future? We are trying to think of service development across the * to support families . In your opinion what would make the most difference to your child and family?
- Of all the needs you have as a family what are the three things that are most important?

End Have we missed anything ?

Appendix 10.

Support Services for Participants

Research Study
Children's Hospice Provision in the *
Support Services for Participants

Sometimes talking about palliative care services can be upsetting. Detailed below are a number of support services available to you as a participant of the above study, should you feel that you need to talk to someone.

*** [hospice] Family Support Team** – This team is available between Monday-Friday 8.00-17.00. They are able to offer general psycho-social support as well as specialist spiritual, bereavement and sibling support. Your child does not have to be using any service at * for you to make contact with this team during the time of the study. The team are aware of this study and will be available to anyone impacted by it. Anything you share will be confidential and will not form part of the study.
Please contact the main hospice number : Tel *

Together for Families Helpline: Tel 0808 8088100 7am – midnight 7 days a week.
This is a helpline provided by Together for Short Lives, the national charity in the UK for children with life-limiting and life-threatening conditions. It offers information signposting and support.

Together for short lives website also has a directory of services -
<http://www.togetherforshortlives.org.uk/families/services/filter/east+midlands>

Contact a Family: Tel 0808 808 3555 Monday to Friday, 9.30am to 5.00pm
Contact a Family provides support, advice and information for families with disabled children. They also have information regarding specific medical conditions and related support groups/associations on their website

<http://www.cafamily.org.uk/medical-information/>

Remember you also have the health professionals who know you and your child who are there to help e.g.

- General Practitioner
- Community Nurse
- Health Visitor
- Social Worker

Enclosure 10 Support Services for Participants Vs. 1, 1st April 2014
Children's Hospice Provision

Appendix 11.

Process of Theoretical Coding and Integration of Datasets

Main Themes	Core categories	Preliminary categories	Codes and focused codes
Coming 'Home'	Crossing the Threshold	Readiness for respite <i>(Ready for respite)</i>	Ready for admission Qualifying for entry Changing social circumstances Entry criteria Difficulty in decision making Searching
		Internal battles	Separation anxiety Parental responsibility and guilt Parental struggles
		Rite of passage <i>(Hospice the only option)</i>	Geographical difficulties Lack of choice and inequities Somewhere like home Right time for respite
	Gateway to Belonging	Attributes of belonging <i>(Creating a sense of belonging)</i>	Characteristics for belonging Safety and security Flexibility Continuity and relationships Expert carers
		Juxtaposition of belonging <i>(A paradox of belonging)</i>	Identity of hospice Labels Belonging that means you will die Security in knowing all in the same boat Hospice family Palliative means death Hypnotic effect of hospice, drugged in the morning Sleep, relief, retreat
		Masters of Disguise and Illusion <i>(Disguise)</i>	Two sides Dual role Confused offer Don't like terminology Disguised
This is Living Now	Balancing the Scales	A life with restrictions	Battleground Isolated Timetabled life Intensity and multiplication Sterility of life
		Impact of loss	Grief and loss Robbed of future, missing out Left behind Identities re-established Ability to change and adapt
	Maintaining Control <i>(Creating our own normal)</i>	Doing life <i>(A different normal)</i>	Do life differently Parental roles Maintaining family Needs of siblings Invaded at home
		Taking control	Mapping own world Maintaining control Safe at home Living for today Desire for normality
Moving Forward	Uncharted waters <i>(Living with uncertainty)</i>	Journey with an inevitable end	Confined by time Know what's on the horizon Uncertainty
		Fear for the future	Transition anxieties Lack of choice
	New Territories <i>(Uncharted waters)</i>	A new generation	Longevity of condition Always a child Teenagers
		The piece of the jigsaw that doesn't fit	Mental capacity Different groups of children Not the right place

Red Italics representing the changing category labels to ensure data conceptually fits.